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From go to woe: family member’s stories of adolescents and young people living with and dying from cancer

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From Go To Woe: Family Member’s Stories of Adolescents and Young People Living with and Dying from Cancer

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A thesis submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

28th October, 2011
THESIS DECLARATION

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

I acknowledge that I have read and understood the University's rules, requirements, procedures and policy relating to my higher degree research award and to my thesis. I certify that I have complied with the rules, requirements, procedures and policy of the University (as they may be from time to time).

Name: Janet Anne Barling

Signed:

Date: 28th October 2011
DEDICATION

This thesis is dedicated to my 'man child' Anthony Barling


Anthony's courage, wisdom and strength during his cancer journey, and his exploration of the cancer landscape, was my inspiration. His perceived presence has made it possible for me to engage with other peoples’ stories of suffering.

Anthony

I will not forget you. You are in my waking thoughts, my sweetest memories, my dearest dreams

I will not forget you. You have touched my soul, opened my eyes, changed my very experience of the world

I will not forget you. I have carved you on my shoulder, I will carry you with me forever

Adapted from Ellen Sue Stern, (2006)
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To the family members who shared their painful memories with me in order to make this thesis possible.

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To my husband Bruce, who supported me by his commitment to the importance of these stories. He provided me with the emotional and physical support, to honour the sensitive and painful stories which are intrinsic to this thesis. He has proved that, despite the despair and sorrow that is a part of our combined story, there is an ongoing commitment to continue our life journey together.

To my daughter Melanie, for her compassion, understanding, support and unending faith in me.

To my son Glen, whose outlook on life encourages me to see things from a less complicated perspective.

To Associate Professor John Stevens for his support and encouragement.

And finally to Chris Game for her editing skill and whose former role as Head of School of Nursing enabled me to fulfill my role as Anthony's mother and still maintain my position as a Nurse Academic.
ABSTRACT

The purpose of this thesis is to uncover, through families telling their stories, the experience of family members following the diagnosis, treatment, dying and death of an adolescent or young adult (AYA) family member. The decision to undertake this research was related to the lack of treatment, support and research for AYAs with cancer (CanTeen, 2005; Ewing, 2005), life stage issues for adolescents and their families (Grinyer, 2002a, 2007a, 2007b, 2008, 2009), and the researcher’s own position as a mother whose adolescent son had died of cancer.

Given the sensitive nature of the research study and the researcher’s own position, the most appropriate methodology to understand this experience was considered to be narrative inquiry. Narrative inquiry uses open-ended questions and allows the person to tell their story in their own time. The methodology also accommodates the researcher’s own experience, due to a common understanding of the experience for both the researcher and the family members, providing the opportunity for rich descriptions of the experience.

Twenty-six people self selected through the media to tell their story, of a family member aged 12-21 who had lived and died of cancer over twelve months previously. The analysis and interpretation involved the development of core stories, which configured and emplotted the family members’ experience from the transcripts. Following this, themes were identified through Taylor’s (2006) computer-assisted thematic analysis that were further organised and coded using the NVivo8 computer software to identify commonalities and differences within the themes. These themes were coded within four stages of the cancer journey - Departure, Exploration, Anticipation and Destination (Armstrong-Coster, 2004).

The following themes were identified in the Departure stage: something not quite right; confirming what’s wrong; being confronted with the diagnosis; and; response to diagnoses. Being informed about treatment; the reality of hospitalisation; watching the inevitability of treatment; staying connected and supportive; recalling what helped; and;
living the quest were themes within the Exploration stage. The Anticipation stage included only one theme; sensing a reprieve. Finally, the Destination stage uncovered the themes of; ending the reprieve; the pronouncement of impending death; changing the focus of care; going downhill; keeping a vigil; experiencing lack of care; feeling overwhelmed; witnessing heroism; maintaining hope; saying goodbye; recalling the moment and extending the living connection. An overarching theme for the stories in this study was isolation for the AYAs and their families. This study further identified issues specific to AYAs and their families and contributes to developing knowledge for this under-researched group of people.
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CHAPTER ONE: INTRODUCTION

“Everything must have a beginning ... and that beginning must be linked to something that went before.”

Mary Shelley, Frankenstein 1831 (Shelley, 1994 original 1831)

SECTION ONE: BEGINNING THE STORY

This narrative research study focuses on the cancer journey for adolescents and young adults (AYAs) and their families, from the time of diagnosis until death. This chapter is divided into four sections. Section one introduces the background and context of the research study, including cancer rates in adolescents and young adults, current issues unique to adolescents and young adults with cancer. Section two introduces the research aims, objectives and significance, my background and choice of methodology for this study. Section three introduces my personal experience of a young person’s cancer journey and a summary of Anthony’s (my son) cancer journey as told by his father. Finally, section four provides the definitions and descriptions for this study.

CANCER IN ADOLESCENTS AND YOUNG ADULTS (AYAS) IN AUSTRALIA

Cancer describes a range of diseases, in which abnormal cells proliferate and spread out of control. It is the major cause of death for all ages in Australia. In 2005, there were 100,000 new cancer cases and over 39,000 deaths due to cancer (Australian Institute of Health and Welfare (AIHW), 2008). The risk of developing cancer increases with age, with four times as many cancers diagnosed in those over the age of 60 years, as in those under 60 years (Australian Institute of Health and Welfare (AIHW) & Australasian Association of Cancer Registries (AACR), 2004).

The most recent demographical study of cancer in Australia identified cancer as the second most common cause of death for young people aged 12-24 years; the most common being injury and poisoning (AIHW 2003). This rates cancer as the leading cause of death from medical reasons in this age group. The AIHW and AACR Report
‘Cancer in Australia’ (2001), generated from the National Cancer Statistics Clearing House, when identifying the age specific incidence of cancer, grouped adolescents aged 15 and above in the 15-44 year age group. A review of the figures in this report suggest that adolescents and young adults (15-24) record a different profile of incidence, mortality and type of cancer in comparison to older ‘young’ adults (25-44) (AIHW & AACR 2004).

Mitchell, Scacella, Rigutto, Thursfield, Giles Sexton & Ashley (2004) indicate that many of the cancers seen in patients aged 10-24 years are common in the paediatric age group. The most common cancers identified in the 0-14 year age group are lymphoid leukaemia, brain and central nervous system, non-Hodgkin’s lymphoma, myeloid leukaemia and cancer of the connective and soft tissue (AIHW & AACR 2004).

The AIHW & AACR (2004) identified melanoma, breast, thyroid, testis and colon cancer as the most common cancers in the 15-44 year age group. A further breakdown of selected cancers by age group demonstrated, with the exception of melanoma and testicular cancer, the most common cancers for the 12-24 year age group are the same cancers as the 0-14 year age group (see Figure 1.1).

Similar findings are found in international research. For example, Stiller (2002) reviewed three large epidemiological studies of cancer incidence in young people in England, the Netherlands and the United States and found in the 15-19 age group, acute leukaemias, lymphomas, central nervous system tumours, bone and soft tissue sarcomas, germ cell and other gonadal tumours, thyroid carcinoma and melanoma accounted for 90% of all the cancers diagnosed. An analysis of the data reveals that of this 90%, 72% of patients aged 15 to 19 year had a paediatric type of cancer, and 15% of the cancers were cancers common in young people, for example, germ cell and gonadal cancers. The other 13% of the cancers identified were cancers that have a higher incidence in young adulthood, such as thyroid cancer and malignant melanoma (see Figures 1.2 and 1.3).
Figure 1.1 Types of cancer in Australian AYAs aged 12-24 (Australian Institute of Health and Welfare (AIHW) & Australasian Association of Cancer Registries (AACR), 2004; O’Brien, Senner, Thomas, Treadgold, & Young, 2006)

Figure 1.2 Percentage of paediatric and young people’s cancer aged 15-19 years
Figures 1.1, 1.2 and 1.3 demonstrate a distinct pattern of incidence for adolescent cancers. Adolescents and young people rarely develop cancers that predominate in older people such as lung, colon and female breast. Furthermore most of the common malignancies in children less than five years of age are also virtually absent in adolescents (Bleyer, 2002; Stiller, 2002).

CanTeen, (the Australian support organisation for young people living with cancer), (2005) in a submission to the Senate Inquiry into Services and Treatment Options for Persons with Cancer, specify that responses to cancer treatment and support can be divided into paediatric and adult categories. The submission advocates for attention to be directed to a forgotten group with specific needs and characteristics, the AYAs. The submission highlights the fact that nearly twice as many 12-24 year olds are diagnosed with cancer in Australia each year, as are 0-12 year olds (CanTeen, 2005). In addition, young people in the 15-24 year age group record a higher mortality rate (4.3 per 100,000 per annum in 2001) than paediatric patients from 0-14 year age group (2.8 per 100,000 per annum in 2001) (AIHW & AACR 2004). Further to this, survival rates for AYAs have fallen 50% behind all other age groups (AIHW & AACR 2004; CanTeen, 2005). These statistics are further supported by a population inventory study on the incidence and survival rate of 12-24 year olds in Northern Netherlands from 1989-2003 (Gaal et al., 2009). They concluded that the incidence of cancer in this age group
increases with age, there was a significant increase in all malignancies over time, there was no improvement in survival from 1989 to 2003, and there was a high risk of second malignancies. Despite this distinct profile for AYAs with cancer, there is no separate registry for adolescents and young people diagnosed with cancer in Australia.

**Current Issues Unique to AYAs with Cancer**

When reviewing the research related to AYAs aged 12-24 with cancer, Ewing (2005, p.3) identified the following problems:

... the gap between paediatric and adult services, no significant improvement in health status since 1960, the least improvement in survival over the last 25 years, a cancer incidence higher and increasing faster in 15-19 year olds than younger paediatric patients, issues not adequately addressed by current systems or models of care, many health care professionals caring for adolescents had little or no formal training in adolescent health, and AYAs’ rights to developmentally appropriate health care information, support and care were breached.

She stated at that time “improvement in outcome may require questions specific to the 16-24 year age group” (Ewing, 2005, p.3). This information suggests that AYAs aged 16-24 with cancer are at a disadvantage within the present health care system.

Some factors identified to account for this disadvantage include: medical issues specific to AYAs with cancer (Bleyer, 2002; Thomas, Seymour, O’Brien, Sawyer, & Ashley, 2006); delay in diagnosis (Bleyer, 2002); fragmented services and lack of access to clinical trials (Albritton & Bleyer, 2003; Bleyer, 2002; Burke, Albritton, & Marina, 2007; CanTeen, 2005; Cole, 2004; A. Mitchell et al., 2004; Newburger, Elfenbein, & Boxer, 2002); and psychosocial/life stage issues (Albritton & Bleyer, 2003; CanTeen, 2005; Klopfenstein & Young-Salame, 2002; Whyte & Smith, 1997).
Medical Issues

Thomas, et al (2006) and Albritton and Bleyer (2003) speculate that cancers in AYAs have a different biology and morphologically similar cancers may be molecularly distinct. Bleyer (2009) summarised recent reports in five of the common types of cancers in AYAs. He concluded that there was an unique array of cancer types in AYAs with age dependent incidence patterns which suggested that biology was different more often than not. In addition, patient tolerance to chemotherapy may be less in adolescents and young adults (Thomas, et al., 2006). This implies that different treatments may be required for AYA cancers.

Pollack, Krischer & Vietta (1991) found that for the majority of solid tumours, the time between symptoms onset and diagnosis increases with age. Albritton and Bleyer (2003) suggest reasons for the delay that include the AYA’s strong sense of invincibility, which may delay visiting a medical practitioner out of denial or embarrassment. Once seen, the AYA may provide poor history to the medical practitioner unfamiliar with AYA communication styles. It is also rare for AYAs to have cancer; therefore symptoms may be attributed to other factors such as physical exertion, fatigue and stress. Albritton and Bleyer (2003) add that young adults are the most underinsured age group in America and many do not have a primary care physician who is aware of the patient’s baseline health status. Also, AYAs engage in their own personal hygiene, so changes that may have been noticed by parents go unnoticed. Lastly, the authors suggest that many health care professionals receive little training in adolescent health and find it difficult to communicate with AYAs about sensitive issues.

Lack of Clinical Trials and Fragmented Services

Cole (2004) suggests that adolescent and paediatric cancer patients have better outcomes when on clinical trial protocols. Some cancers that affect adolescents have a good prognosis, for example, Hodgkin disease and gonadal tumours have good survival rates whether or not they are part of a clinical trial. On the other hand, the survival rate for other AYA cancers such as acute myeloid leukaemia, acute lymphoblastic leukaemia, rhabdomyosarcoma, osteogenic sarcoma and Ewing’s sarcoma, have much lower survival rates in AYAs than in younger patients (Cole 2004).
Children and adolescents with lymphocytic leukaemia, non-Hodgkin’s lymphoma, neuroblastoma, medulloblastoma and rhabdomyosarcoma showed increased survival when on clinical trials and in specialist centres (McTiernan, 2003). Despite this, adolescents appear to not have equal access to clinical trials. For example, Bleyer, Tejeda, Murphy, Robinson, Ross and Pollock et al (1997) identify that most children (aged 0-14) in the USA are on clinical trials and/or treated in specialist facilities, in comparison to adolescents (15-19) where 10% are on a clinical trial and 11% are treated in specialist facilities. As a result of this underrepresentation in clinical trials, tumour samples are less likely to be collected and banked. (Cooperative Human Tissue Network data as cited in Burke et al 2007). This limits the researcher’s ability to ask questions as to different prognostic outcomes with age given the same histology; questions such as - is it related to change in the host biology or hormones (Burke, et al., 2007). This underrepresentation in clinical trials results in minimal research on AYA specific cancers with little information about the biology, outcomes and the role the host plays for AYAs with cancer (Burke, et al., 2007).

Newburger et al (2002) cited an American workshop sponsored by the National Cancer Institute on the recruitment of AYA cancer patients to clinical trials, which emphasises the need to investigate the barriers to participation. McTiernan (2003) predicted that, although not formally assessed, figures in the UK and Europe would be similar to the USA. McTiernan (2003) connected the lack of participation to lack of equal access to centres that specialise in paediatric and, sometimes, rare malignancies that present in AYAs. Burke et al (2007) speaks of different goals for clinical trials within the paediatric and adult oncology that hinder collaborative efforts and leaves the AYA in a gap that impedes progress. These findings suggest the fragmentation of adolescent care between adult and paediatric oncology (McTiernan, 2003).

This fragmentation is demonstrated with Australian statistics from Victoria where in 2003, 366 patients were diagnosed with cancer between the age of 15 and 30 years. The Peter MacCallum Cancer Centre, a Centre of Excellence in Victoria for the treatment of cancer, treated 105 (29%) of these cases, and the remaining 261 (71%) were treated in 66 private and public hospitals across Victoria; with 49 of these hospitals treating fewer than three patients each (Thomas, et al., 2006). Evidence from a variety of studies (Davis, Dahlberg, Myers, Chen, Steinhorn, 1987, Feuer, et al, 1994, Horowotitz, et al, 1992, Bacci et al, 2004) suggests that many cancers affecting young people, such as
germ cell, leukaemia, and lymphoma and bone cancer, have better outcomes in centres with a higher concentration of expertise (as cited in Thomas et al 2006). Despite this, fewer AYAs are referred to comprehensive cancer centres than patients in any other age group (Phillips, 2009).

The lack of clinical trials and fragmented adolescent services has resulted in cancer survival for AYAs that lags behind children and older adult groups. Mitchell et al (2004, p.59), in a study of AYAs treated for cancer in Victoria, found that the cancer incidence had increased by 30% in those aged 10-24 years between 1993 and 2001. In addition, mortality rates in AYAs with cancer have been slow to decline. The study found 38% of adolescents aged 10-19 were treated in clinical trials in paediatric teaching hospitals, in comparison to 3% in adult hospitals. Only 4% of young adults aged 20-24 years were treated within clinical trials. The study demonstrated, in the case of bone tumours, significantly more adolescents aged 10-15 (46%) were treated within clinical trials than those aged 16-19 (5.5%). Those treated in the paediatric hospitals had a higher incidence of five-year survival. This is despite clinical trials for paediatric cancers being available to AYAs and the development of national disease specific collaborative group trials within the adult system of which AYAs are often eligible (Phillips, 2009). This lack of recruitment of adolescents and adults over 15 years could be explained by the fact that 86% of the adolescents aged 16-19 in this study, were treated in adult care facilities where clinical trials would be related to adult cancers and not the paediatric cancers, with which the majority of adolescents and young people over 15 are diagnosed. This is confirmed in Downs-Canner and Shaw (2009) study which compared the number of clinical trials for AYAs in two affiliated paediatric and adult hospitals, the Children’s Hospital Pittsburg and the University of Pittsburg Cancer Institute. In the paediatric hospital 26% were enrolled in clinical trials compared to 4% in the affiliated adult hospital. Further, Ramanujachar, Richards, Hann and Webb (2006) conducted a systematic review of all international published clinical trials for AYAs with acute lymphoblastic leukaemia. The AYAs were treated in both the paediatric and adult system. The review sought to determine whether AYAs should be treated with paediatric or adult type protocols. They concluded that AYAs appeared to have a survival advantage when treated with paediatric protocols. Newburger et al (2002) specify this lack of access and referral to specialist centres has an impact on their quality of care. Such centres have immediate access to multidisciplinary teams who specialise in the type of cancers AYA are likely to have.
PSYCHOSOCIAL ISSUES

There are multifaceted issues that may affect cancer care in this age group. For example, the care of AYA cancer patients needs to consider the physical, intellectual and emotional developmental stage of the young person, in addition to age specific issues such as socialisation, education and emotional support (Newburger, et al., 2002). The transition from one life stage to another is complex and each individual follows a different path and develops at a different rate. The AYA may be living at home and dependent on family and friends, or totally independent with a spouse, children and employment. They may be insightful of their illness and compliant, or convinced of their invincibility and immortality and non-compliant. They may be open and talkative, or shy and unreachable (Albritton & Bleyer, 2003).

Some of the possible psychosocial issues, that are specific to AYAs, include: balancing the needs of autonomy and independence with parental demands, isolation from peers, delayed social development, negative body image, absence from education, work and the community, concern over sexuality, intimacy and fertility, strain on intimate relationships, and presence or absence of a sense of hopefulness (Albritton & Bleyer, 2003; Phillips, 2009, Thomas, et al., 2006; Whyte & Smith, 1997).

A common thread running through many problems affecting young people with cancer is isolation. Isolation can be from peers and community, from peers finding it difficult to understand the experiences of a young person with cancer, and from rural distances. Young people may also experience isolation due to rarity of some tumours, or due to health care professionals having difficulty communicating with young people and avoiding emotional discussions. Isolation may also come from obstacles to the development of appropriate support services and participation in clinical trials (Thomas, et al., 2006).

Johanna’s story as told by her mother (reprinted from Princess Margaret Hospital media release in the CanTeen Newsletter, 2005 p.4) illustrates some of these isolation issues faced by young people diagnosed with cancer.

(Johanna’s mother) Helen said Johanna had a very difficult time while she was ill, because she had been admitted to Sir Charles Gairdner Hospital (SCGH) which is an adult hospital.
“She had never been in hospital before - it was a terrifying time for her, especially on her first night in an eight-bed ward,” Helen said.

Johanna’s illness, osteogenic sarcoma, was classified as a “childhood” cancer, so her treatment was spread between SCGH [adult hospital] and Princess Margaret Hospital (PMH) [paediatric hospital].

“The adult hospitals are great but they expect people to behave like adults. Teenagers lose their confidence entirely,” Helen said.

“Later on, when Johanna became involved with CanTeen at PMH, we commented how much happier she would have been if she had stayed at PMH instead.”

“However, we were both concerned at how teenagers had to reside with younger children at PMH, which was not always practical in terms of bedtime and privacy.”

Johanna’s story suggests AYAs are a forgotten group who are orphaned in the system (Phillips, 2009). Albritton and Bleyer (2003, p 2593) explain, “these patients have special needs that are not only unique to their age group, but also broader in scope and more intense than those at any other time.” Soliman and Agresta (2008) identify the diagnosis of cancer has a profound effect on the AYAs and their families. They say many factors shape how the AYA will react to the many challenges they encounter. These include, “the patient’s age, personality, faith, education, culture, family, social support, financial means, prognosis and quality of life” (Soliman & Agresta, 2008, p. 59). The medical team needs to ensure that they provide the information and tools to help AYAs with cancer (Soliman & Agresta, 2008).

Despite this Thomas et al (2006) claims that:

... age specific psychosocial supports for young people with cancer do not currently exist in the Australian adult hospital system. Because most young people with cancer will be treated in a range of adult hospitals, it is possible that the lack of access to well designed psychosocial supports may lead to unnecessary deaths from cancer, because clinicians are unable to deliver curative therapies (p.305-306).
CanTeen (2005, p.3) contends that:

... treatment and support, as well as research, mostly focuses on children or on older adults, but not on adolescents and young adults. At the same time, it has been repeatedly demonstrated that significantly improved outcomes are possible with better treatment and support specifically designed for adolescents and young adults.

Although the second highest cause of death for this age group, cancer is still rare. Therefore, the isolation and invisibility within the health care system that the AYA and their family experience when receiving treatment, are further compounded if the young person is dying. The health system can provide support for families who have an adult member dying (in the adult system) or families whose child is dying (in the paediatric system). The majority of young people aged 16 and over are cared for in the adult system, where support is focused on the dying trajectory of a parent or a partner in the older age group.

**Section One: Summary**

This section provided the context for this research study by describing literature that demonstrates that AYAs living with cancer are a group of people who do not do as well, in terms of treatment and outcomes, as children or adults with cancer. There is a lack of understanding, resources and support for AYAs living with cancer and their families.

Therefore, the following identified issues have informed this study for this group of people:

a) lack of treatment, support and research for young people (CanTeen, 2005; Ewing, 2005);

b) lack of space or place for AYAs and their families in the health care system;

c) life stage issues for the adolescents and their families (Grinyer, 2002a).

These issues determined the research aim and objectives of this study.
SECTION TWO: INTRODUCTION TO THIS STUDY

Research Aim and Objectives

The aim of this study was to uncover, through family members telling their stories, their experience following the diagnosis, treatment, dying and death of an adolescent or young adult member (aged 16-25 years).

The objectives were:

1. through storytelling, to develop a deeper understanding of the experience of family members through the trajectory of diagnosis, treatment, dying and death of an AYA with cancer;

2. identify issues that influence the experience of family members with an AYA living and dying of cancer.

Significance

The significance of this study is in its potential to identify issues for family members and AYAs with cancer, from the time of diagnosis to death. The identification of these issues will increase the understanding of health care professionals for this ‘forgotten’ group of people and their families. The study will also increase knowledge to assist in developing health care services and health care professionals, who are aware of the unique needs of this group.

The Researcher’s Background and the Choice of Methodology

This section provides information relating to the knowledge, skills and experience, which I brought to this study in relation to the chosen methodology, and clearly demonstrates my multiple positionality as a researcher, mental health professional, partner, and mother of an AYA who was diagnosed with, and eventually died of, cancer.

I am a Registered Nurse with general and psychiatric nursing certificates, a Diploma of Applied Science with a sub major in nurse education, a Bachelor of Arts with a major in
psychology, and a Master in Nursing with a major in mental health. I have over 25 years experience working in the area of mental health and I now teach mental health and loss, grief and dying in the nursing curriculum at a university.

My mental health experience includes case management, assessment interviewing, crisis assessment interviewing, and generic counselling across all age groups, with individuals, couples and families. In my work, I have used a broad range of therapies such as: solution-focused therapy, narrative therapy, family therapy and cognitive behavioural therapy. Counselling knowledge and experience in mental health has resulted in the development of expertise in mental health and this knowledge and skills were particularly important for this study, especially family and narrative therapy. Counselling knowledge and experience will enable me to listen to a person’s story and encourage the person to provide a thick description of their experiences. My expertise has also prepared me to be cognisant of professional boundaries and to be aware if a person requires professional help. Therefore, my work background provided me with the means to use the method of narrative inquiry for this research topic.

Added to my professional experience I was also drawn personally to the research topic, due to my experience of being a mother whose own 17 year old son died of cancer. Therefore, I am acutely aware of an adolescent’s and an adolescent’s family cancer journey. The experience of my son dying of cancer resulted in my questioning where these people and their families fit in the health care system and what I could do to possibly raise awareness for this group of people.

My work background and the sensitive nature of the study pointed to narrative inquiry or storytelling being the most appropriate research methodology. Storytelling asks participants to tell stories to the researcher as a narrative or life history, and is especially useful for studying transformations and transitions in people’s life (Holloway, 1997). Narrative refers to “a meaning structure that organises events and human actions into a whole” (Polkinghorne, 1988, p.18). “Narrative is more than a single story, it is the collective ‘stored wisdom’ of people’s individual stories” (Emden, 1998b, p.35). Thus, narrative inquiry is a process where individual stories can provide increased meaning and understanding to the aims of this study. The theoretical underpinnings of narrative inquiry, with a justification for this approach in this study, are described in more detail in Chapter Three of this study.
In addition, narrative requires that the researcher recognises the importance of taking on the role of “the other.” To recognise the specific features of “the other”, it is required to know what story in which the actor is participating (Sarbin, 1986). Bruner (1987) states:

... life stories must mesh, so to speak, within a community of life stories, tellers and listeners must share some “deep structures” about the nature of a “life,” for if the rules of life telling are altogether arbitrary, tellers and listeners will surely be alienated by a failure to grasp what the other is saying or what he (sic) thinks the other is hearing (p. 21).

As such the ability to construct meaning from a story relies on the background knowledge the researcher brings to the story. This understanding is increased by an empathetic understanding of the “other”, upon having shared the same experience as the “other” (Franzosi, 1998, p.547). This background knowledge or empathetic understanding will influence how and what is included in the stories. In addition, the researcher’s interpretation and understanding of the stories will be influenced by a shared understanding of the experience. In summary, the decision to use narrative inquiry as the research methodology was related to the research aims and objectives, the exploratory nature of the research, and the researcher’s own experience in relation to the research question.

**Section Two: Summary**

In this section I placed myself within the context of the research study as a researcher and a mother. My qualifications and experience were identified to show the contribution I could make to the study. I also explained why narrative inquiry was a suitable methodology for the research study, given my work expertise, the sensitive nature of the research study, and my own experience with an AYA with cancer who eventually died.

The next section describes the cancer journey of my son, Anthony, and illuminates further the reasons underlying the choice of the research aims and objectives.
SECTION THREE: ANTHONY’S STORY

As mentioned previously, the idea for this research originated from my own experience of caring for my adolescent son, when he was diagnosed and eventually died of cancer. During the process of diagnosis, treatment, dying, death and the grieving that followed, it became evident to myself and my family, that the present system of care finds it difficult to accommodate the special concerns and issues that are typical for this group of patients and their families. This assumption was further confirmed when reviewing some of the relevant literature and in discussion with other families, who have travelled the same path. For example, as revealed in Grinyer’s research, Helen, a mother whose son died of cancer, could find no written material that specifically addressed the needs and life stage issues of young people with cancer and the problems their parents might encounter (Grinyer, 2002a).

In March 2001 my son Anthony, who had turned 16 three days earlier, was diagnosed with rhabdomyosarcoma, a rare form of childhood cancer. As we progressed along this journey we would find ourselves in a health system that had little understanding of our family context. Due to our home being in a rural/regional area of NSW, at the time, there was limited access to cancer services in the area. This resulted in Anthony being cared for in cancer treatment units local and interstate, metropolitan orthopaedic wards, cancer wards surrounded by 70 to 80 year old men, in a single room in the local paediatric ward and in an isolation ward for his stem cell transplant. In all he was treated in seven different hospitals, both private and public.

The diagnosis and treatment occurred at a time when Anthony was establishing himself with an extended group of friends and beginning relationships with the opposite sex. The family was caught with the developmental dilemma of protecting and caring for Anthony because of the diagnosis of cancer, and allowing him the freedom to establish himself with his peers and experience the normal developmental tasks of adolescents.

In November 2001, he was diagnosed with metastasis (with a very poor prognosis), thus began an intensive regime of radiation and chemotherapy. The majority of Anthony’s treatment was undertaken in the adult health system where Anthony was located with older men, some demented, some dying, and some having treatment to prolong their life. The system had no resources to accommodate adolescents and their families. Despite the intensity and the side effects of treatment, Anthony still sought to maintain
his relationships with his peers and to appear as normal as possible. Anthony died at home, cared for by community nurses and the palliative care team and his family. Anthony’s father Bruce has produced a summary of this journey in Table 1.1.
<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Treatment</th>
<th>Result</th>
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<tr>
<td>March 2001</td>
<td>GP registrar tells us that Anthony has a rare cancer called Rhabdomyosarcoma and needs to have a CT scan and bone scan and go to Sydney for treatment.</td>
<td>CT scan shows that the tumour is 3.2cm in diameter in his chest wall</td>
<td>Diagnosis of Rhabdomyosarcoma This is a rare type of paediatric cancer which grows quickly and metastasises early.</td>
<td>Absolutely devastated and scared.</td>
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<td>March 2001</td>
<td>Flew to Sydney RPA hospital for appointment with surgeon and medical oncologist. Oncologist is optimistic about a cure as the tumour is encapsulated and no evidence of any spread.</td>
<td>Explained that the treatment will involve 4 cycles of chemotherapy to shrink the tumour then surgery to remove what remains of the tumour and resect the chest wall, 2 more cycles of chemotherapy to ‘mop up’ any remaining microscopic cancer cells.</td>
<td>As treatment may cause infertility Anthony is referred to the Androgyny Clinic at Concorde Hospital for sperm collection. Three samples collected over 4 days. Good swimmers reported!</td>
<td>Confronting the challenges of what the treatment will do.</td>
</tr>
<tr>
<td>March to May 2001</td>
<td>First chemotherapy treatment at RPA, 2nd at RPA, 3rd and 4th Cycles of Chemotherapy at Lismore Base Hospital, Cancer Care Unit three weeks apart.</td>
<td>Chemotherapy (three different drugs): Doxorubicin, Vincristine, Cyclophosphamide.</td>
<td>Some nausea and loss of appetite.</td>
<td>This is really happening.</td>
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<tr>
<td>June 2001</td>
<td>Removal of tumour at RPA, the day after Melanie (sister) returns from overseas. Discharged from RPA after 6 days to friend’s house in Sydney for convalescence.</td>
<td>Chest resection removes remains of tumour, two ribs and the nerves on the underside of the ribs. Returns to ward with chest tube in. PCA effective and moved to oral analgesia within 3 days.</td>
<td>Surgeon is happy with the surgery, said it was hard to find the tumour as it had shrunk so much with chemotherapy. Oncologist later advises that pathology on the tumour showed a 98% kill rate of the cancer cells with chemotherapy.</td>
<td>High anxiety about the surgery mixed with anticipation that this would save Anthony's life. So very thankful that we have good friends in Sydney who look after us in so many ways.</td>
</tr>
<tr>
<td>Date</td>
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<tr>
<td>October 2001</td>
<td>Chest CT Scan to check for any regrowth.</td>
<td>CT scan reveals no tumours.</td>
<td></td>
<td>Enormous relief that this was the first step to a cure.</td>
</tr>
<tr>
<td>November 2001</td>
<td>Back pain develops over a period and continues to get worse. Surgeon contacted and advised us to get a bone scan.</td>
<td>Bone scan and CT scans carried out at Lismore and results taken immediately to GP for advice.</td>
<td>Scans reveal metastases in the left knee. GP advised us to have a Christmas to remember.</td>
<td>Sheer terror and despair.</td>
</tr>
<tr>
<td>December 2001</td>
<td>Referred to Royal Brisbane Hospital (RBH) for radiotherapy.</td>
<td>Needed to get an MRI for radiation planning – unable to get one quickly at RBH so went to Greenslopes Private Hospital. Anthony in significant pain. Results of Sydney PET scan sent to RBH. At major risk of cord compression. Radiation commenced on chest, spine and knee. Radiotherapy: 28 Grays over ten sessions</td>
<td>MRI results: “Multiple metastases identified the most marked are at T3 and T5 where there is extradural extension of disease causing mild cord compression ... both have a high likelihood of causing cord compression in the near future”.</td>
<td>Alarm at prospect of cord compression and need to deal with the increasing pain levels.</td>
</tr>
<tr>
<td>February-May 2002</td>
<td>Decision made at Royal Brisbane Hospital to treat from the beginning using standard Rhabdomyosarcoma protocols with a view to moving to high dose chemo and stem cell transplant</td>
<td>Treatment involves 4 day inpatient chemotherapy at RBH every 3 weeks and other weeks Vincristine only at LBH. Arrange to have a Port-a-cath inserted in upper chest. At St Vincent’s in Lismore.</td>
<td>Oncologist comments that in the early days with the rapid spread of the disease there was not much optimism, but now very impressed with response to treatment.</td>
<td>Hospital in Brisbane is draining. Ant can’t wait to get out. Doesn’t listen to music because he doesn’t want to associate it with this experience. The wards are old and he is mixed with much older men – very depressing.</td>
</tr>
<tr>
<td>Date</td>
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<td>June 2002</td>
<td>Referral to Bone Marrow Transplant Specialist. He wants to know what we have been told. Emphasises that this is not a cure but a chance of remission for between 6 months – 5 years. At the end of the appointment he says he can get Ant walking for his Year 12 formal after the stem cell transplant.</td>
<td>Admission to Brisbane Private Hospital for insertion of Hickman Line and commencement of high dose chemotherapy (Melphalan &amp; Busulfan) to totally wipe out Anthony’s immune system. Transfer to Bone Marrow Transplant Unit at RBH. When white cell count is zero, Anthony’s own stem cells are transfused back into his body.</td>
<td>No hair at all not even eyebrows. On crutches for knee. Being fed intravenously. A total of 5 drips on 5 pumps going through the Hickman line and port-a-cath. In hospital for 3 weeks with limited visitors and having to wash hands and gown up before entering his ‘cell’ for the next 3 weeks.</td>
<td>Waiting for the cell count to go down to zero and then after transplant willing it to come up. Some optimism that this treatment will give Anthony some more time but not a cure – try not to focus on the last bit.</td>
</tr>
<tr>
<td>8 October 2002</td>
<td>Referral to orthopaedic surgeon notes that this is not curative but may provide more time. Bone marrow transplant doctor asks us to get a chest xray before coming to Brisbane. Total Knee Replacement surgery at The Wesley hospital in Brisbane.</td>
<td>Chest X-ray reveals a major pleural effusion in the left lung. On arrival at The Wesley Hospital we find the haematologist and show him the chest X-ray. He consults the anaesthetist and returns with the words that the anaesthetist believes he will be &quot;OK for the surgery&quot;. Total Knee Replacement operation goes ahead.</td>
<td>&quot;The distal third of the femur has been resected and a reconstructive prosthesis is in place. The patella has been preserved. The day after surgery they take Ant to radiology and drain one and a half litres of blood stained fluid from his chest.</td>
<td>Too scared to ask what is happening. What is causing the pleural effusion? Later we realise that this operation was sheer folly and should not have been carried out. Feelings of guilt that we didn’t protect Ant mixed with anger at the system that allowed it to go ahead.</td>
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<tr>
<td>November 2002</td>
<td>Ambulance called to take Anthony to Lismore Base ED suffering shortness of breath.</td>
<td>Another litre of fluid drained from chest and admitted to Children’s ward with drain in situ. After a few days it is decided to try a pleuradesis procedure to stop the fluid build up.</td>
<td>Pleuradesis performed in theatre and surgeon tells us that Anthony’s left lung is just full of tumour. Physician talks to us about palliative care. Time to go home.</td>
<td>Realisation that the end is approaching. Contact the RBH oncologist for any last chance treatment – nothing on offer.</td>
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Table 1.1  Summary of Anthony’s Cancer Journey as told by his Father, Bruce (cont.)

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<th>Date</th>
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<tr>
<td>30 November 2002</td>
<td>After several days of not eating, occasionally sucking on ice, pain patches and Rivotril to reduce anxiety. ‘Hashish’ drops help ease Ant’s situation. He likes to be carried to different locations in our house – the couch, our bed, his bed. On this day I tell him no moving today as my back is very sore from the lifting. This is OK with Ant.</td>
<td>Lying on his bed in his room, dozing. Ant complains that his back is ‘caning’. Janet (mother) gets on the bed to rub it, Mel (sister) in the room. Janet calls out ‘Bruce’, I turn and see that Anthony’s eyes are fixed. Mel says shall I get Glen (brother) just as he walks into the room. We are all together, including the dogs. Ant has taken his last breath and it happened so quickly without fuss – just like him to slip away like this. We all touch his body and cry and profess our love. It is 1.20pm. We open the windows in his room, and play JBTs ‘Ocean’ really loud. We toast him with champagne.</td>
<td>Pain and suffering is no more for Anthony – almost blessed relief, we who are left behind will carry it now. We are all alone. This is the end of a long and painful journey for Ant and our family. It is also the start of another journey of our profound grief and how we remember Anthony and keep him a part of our family. This will let Ant’s spirit leave and rise up and be free at last!</td>
<td></td>
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</table>

Adapted from (Zammit, 2008)

A more comprehensive account of this journey is documented in Appendix A
The trajectory of Anthony’s diagnosis and eventual death required that our family reinvent itself on many occasions, as situations changed and the family had to renegotiate roles and responsibilities within the family structure. This constant reassessing was more difficult, given the life stage of Anthony and the family responsibilities associated with this developmental stage. This was compounded by a perceived lack of understanding in the health system, which provided care through the lens of adult care. This resulted in a sense of isolation for our family. The support of other adolescent families travelling a similar path was unavailable, as it was rare to find another family travelling the same journey within the system. As a result, the stories we heard, hopeful or sad, were related to the anxieties of a partner, or adult children of older adults living with cancer. These stories, at the time, were difficult to incorporate into our experience with our adolescent son. In addition, the adult system did not have the expert knowledge required to understand adolescent development and their families and the effect of a cancer diagnosis for a young person and a family at this stage in a young person’s life.

Since his diagnosis and eventual death, our family has been trying to create some meaning around his life, his death and how we negotiate the future. This reflection lead me down the path of wanting to hear other families’ stories, in the hope that they may provide some increased understanding of the experience of families of young people who have died. This increased understanding may facilitate accommodation and adjustments for AYAs and their families being cared for in the present health system.

Given my own personal experience this study is more than just a research study in order to gain the qualification of a PhD. As Grinyer (2002a) says, at this particular point in time research and publication dominate academic life. Grinyer (2002a) believes that this culture may lead to the exploitation of vulnerable people for career advancement or for the benefit of others involved in the research and publication process. This was not the purpose of this study and, from its commencement, I was mindful that the target audience would be not only academics but also AYAs, family members, health care professionals and members of the general population who seek to develop some understanding of the unique needs of the family members and AYAs.. With this in mind, this study is written with the intent of it being accessible to others besides academics.

SECTION FOUR: DEFINITIONS AND DESCRIPTIONS
Defining Adolescence and Young Adulthood

Thomas et al (2006) identify that the definition of AYA cancer in adolescence and young adulthood is evolving with time, with consideration given to the young person’s developmental stage, pathology and health outcomes. Turner-Henson (2005) identified adolescents as a vulnerable population, because of the rapid changes that occur during this period of life. This stage in life is characterised by more biological, psychological and social role changes than any other transitional period, excluding infancy (Williams, Holmbeck, & Greenley, 2002). There are two transitional points during this rapid stage of growth and development: 1) the transitions from childhood to early adolescence, and 2) the transition from late adolescence to adulthood (Williams, et al., 2002).

The transition into adolescence from childhood is more clearly identified than the transition to adulthood. The transition into adolescence is marked by the biological changes of puberty, whilst the transition from adolescence to adulthood features sociological events, such as completing one’s education, beginning a steady job, getting married or having children, achieving social and economic independence, gaining freedom from parents and establishing an adult identity (Harvey & Finch, 2008; Moshman, 2005; Smetana, Campione-Barr, & Metzger, 2006). “The prolonged dependence on the parental role, due to increasing numbers in higher education, student debt, and high house prices” (Harvey & Finch, 2008) results in these transitions occurring later in contemporary society. As such, the distinction between adolescence and adulthood is sometimes difficult and many of the issues that are specific to an adolescent are also relevant to a young adult. The literature is now identifying the transition of childhood to adolescence, adolescents, and adolescents to adults as a distinct group of people with similar life stage issues. This distinct group of people is identified as adolescents and young adults (AYAs).

There are differences in the literature as to which age groups are best defined as AYAs. CanTeen’s membership is within the age group of 12-25 years of age whilst OnTrac, the recently formed comprehensive cancer-care program for adolescents and young adults at the Peter MacCallum Cancer Institute in Melbourne, Australia, has an age range of 15-30 years. Coscarelli (2003) suggests the developmental tasks of AYAs might be more importantly defined than a particular age. However, the United Nations defines individuals 10-19 years as adolescents and 15-24 years as youth (United Nations Assembly, 1985). Taking into account these considerations, the age range for this study

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is 16-24 years, the period from late adolescence to early adulthood. Sixteen was seen as an appropriate beginning age for adolescents as, the majority of recently diagnosed 16 year olds, with cancer, are treated within the adult system, and are negotiating the life stage of autonomy and independence. Twenty four was seen as an appropriate cut off age for young adults, based on the United Nations definition of youth and the expectations that the majority of AYAs over 16 would have completed the life tasks to achieve autonomy and independence.

**Explanation of other Key Terms**

The following key terms essential for understanding the content of the thesis are defined in this section.

*Adolescence and Young Adult (AYA):*

A young person between 16 and 24 years (United Nations Assembly, 1985).

*Family Members:*

Members of a family who have experienced an AYA live with and die from cancer and who self selected to be a participant in this study.

*Health System:*

The care that is delivered in institutions and in the community to people who require medical assistance or treatment. The system includes both private and public health services, profit and non-profit organisations and voluntary agencies.

*Paediatric Health System:*

Specialises in the delivery of health services to children aged 0-18 years.

*Adult Health System:*

Specialises in the delivery of health service for adults and young people aged 16 years to death.

*Palliative Care:*
Is a system of care that improves the quality of life of patients and their families facing life-threatening illness. Particular attention is given to the relief of suffering by early identification through assessment, to treat pain and other symptoms, and the provision of psychological, spiritual and emotional support.

**End of Life Decisions:**

These are the decisions that patients and families make, in consultation with health care professionals when the patient has a progressive life limiting illness, as to how the dying process is to be managed.

**CanTeen:**

*An Australian organisation which aims to support, develop and empower young people aged 12-24 years living with cancer.*

**Peter MacCallum Cancer Centre:**

Is Australia’s only public hospital solely dedicated to cancer care.

**onTrac@PeterMac Victorian Adolescent & Young Adult Cancer Service:**

Is Australia's leading multidisciplinary health care team that offers specialised, age appropriate care to Adolescent and Young Adult (AYA) cancer patients treated within adult hospitals.

**Stylistic Features of the Thesis**

The citation style in this thesis conforms to the APA (2005) guidelines. For example, single inverted commas are used to express clichés and colloquialisms. Double inverted commas are used to express direct quotes of no more than 40 words and the spoken word.

Indented paragraphs of 1.0 cm from the left margin are used to express direct quotes of more than 40 words, with no inverted commas.

Personal pronouns such as ‘I’, ‘my’, ‘me’ and so on, have been used in this document instead of ‘the researcher’. This choice fits with the immersion of the qualitative
researcher in the study as a person who is interested actively in other people’s stories of their experiences, rather than a researcher who takes an objective, distanced stance.

Table 4.1 lists the family member’s relationship to the AYA, informations about the AYA’s cancer and death and the type of interview. This table has been laminated and placed in a folder at the back of Volume 1 of this thesis as a quick reference for the reader.

In Chapter Five the four family members’ exemplar core stories, and reflections of the other family members’ core stories, are presented in Arial 12 pt font.

The themes and subthemes created from the family members’ stories, and selections of the family members’ stories supporting the themes and subthemes, are presented in Chapters Six and Seven and are represented in italic Palatino Linotype 12pt font and indented 1.0 cm from the left and right margins.

Table 5.1 lists the family member’s relationship to the AYA and the system of care in which the care occurred. This table has been laminated and placed in a folder at the back of Volume 1 of this thesis as a quick reference for the reader.

Table 6.1 and Table 7.1 lists the themes and subthemes for this thesis. These tables have been laminated and placed in a folder at the back of Volume 1 of this thesis as a quick reference for the reader.

With the family member’s permission, the family members and AYAs real names are used in this study. This was seen as a means of creating a testament and legacy to the AYA who had died.

**Chapters in Thesis**

The chapters in this thesis regularly cite older scholarly literature. This is in response to the limited research, specific to AYAs and family member’s experience of living with and dying from cancer. This older literature is still seen as relevant to the discourse associated with this thesis.

The present Chapter provides the background to the purpose of this research. This background included cancer rates in AYAs, current issues unique to AYAs with cancer, the research aims, objectives and significance, my background and motivation as the
researcher, the methodology of choice, my personal experience of a young person’s cancer journey, and life stage issues for AYAs generally.

Chapter Two reviews the literature that supports this research study and the use of narrative inquiry in the study of cancer and death and dying. The literature is reviewed using key words associated with the AYA cancer and dying, and family members’ experience of an AYA with cancer and the dying process. From the review of the literature, the need and justification for the research aims and objectives will be indentified. In addition, the use of narrative inquiry within cancer and dying research will be identified providing support for the use of narrative inquiry for this research.

Chapter Three discusses and justifies narrative inquiry as an appropriate methodology for this study. The interpretive methodology of narrative inquiry is introduced and its suitability for the topic of this research study explored. Contemporary narrative theories that have contributed to my understanding of narrative and the influence on the study are examined. How narrative accommodates the sensitive nature of the research topic and my own subjective experience is considered.

Chapter Four introduces the reader to the method and processes that were used to conduct this research study. The ethical approval process is reviewed to ensure the safety of the family members and myself in this sensitive area of research. The research design is introduced which includes the recruitment of family members, the narrative interview process, the method of data collection and the designed narrative method of data analysis. Finally, the limitations of narrative inquiry and the trustworthiness and rigour of this study are discussed.

Chapter Five presents four exemplar core stories, in addition to reflections on the remaining core stories. The core stories of the reflections are found in Appendix J. These core stories are developed through the process of emplotment and configuration and summarise individual and family experiences of an AYA patient living and dying of cancer, in both the paediatric and adult health systems.

Chapter Six present the themes and subthemes identified in the creation of the family members’ core stories within the following stages of the cancer journey; Departure, Exploration and Anticipation (Armstrong-Coster, 2004). Themes were identified
through Taylor’s (2006) computer-assisted thematic analysis that were further organised and coded using the NVivo8 computer software. The implications of the commonalities and differences within these themes are discussed.

Chapters Seven, present the themes and subthemes identified in the creation of the family members’ core stories within the Destination stage of the cancer journey (Armstrong-Coster 2004). As with chapter six themes were identified through Taylor’s (2006) computer-assisted thematic analysis that were further organised and coded using the NVivo8 computer software. The implications of the commonalities and differences within the themes of the Destination stage are discussed.

Chapter Eight provides an overview of the research study, it’s purpose, the methodology, insights gained, implications for best practice models, suggested further research and limitations of the study.

**CONCLUSION**

This Chapter provided a brief overview of some of the current issues for AYAs and their families when an AYA family member is diagnosed with cancer. This provided an explanation for the need to develop a greater understanding of this unique group of people. My own motivation to conduct this study, due to the death of my 17 year old son, is also explored. The reader is introduced to the arrangement of the thesis and other details that will assist in the reading of the thesis.

The research aim was to story the experience of family members who had an AYA family member live with and die from cancer. The analysis of the stories provided a meta-narrative with themes within Armstrong-Coster’s four (2004) stages of the cancer journey, Departure, Exploration, Anticipation and Destination. Themes for the Departure stage were something not quite right; confirming what’s wrong; being confronted with the diagnosis; and response to diagnoses. Being informed about treatment, the reality of hospitalisation, watching the inevitability of treatment, staying connected and supportive, recalling what helped and living the quest were themes within the Exploration stage. The Anticipation stage included only one theme sensing a reprieve. Finally, the Destination stage uncovered the themes of ending the reprieve, the pronouncement of impending death, changing the focus of care, going downhill,
keeping a vigil, experiencing lack of care, feeling overwhelmed, witnessing heroism, maintaining hope, saying goodbye, recalling the moment and extending the living connection. An overarching issue for the stories in this study was isolation and invisibility for the AYAs and their families. This interpretation and analysis provided further insights into issues specific to AYAs and their families and contributes to developing knowledge for this under-researched group of people. In order for the meta narrative to be stories and the themes identified I was required to follow a identified research process. The first step in this process is the literature review.

The next chapter discusses, through an in-depth review of the literature, the psychosocial issues which impact on AYAs and their families when an AYA family member is diagnosed with cancer and eventually dies.
CHAPTER TWO: LITERATURE REVIEW

Why tell the story?

“There is nothing like looking, if you want to find something. You certainly usually find something, if you look, but it is not always quite the something you were after.”

J.R.R. Tolkein (Think Text.com Quotations, online March 2011)

INTRODUCTION

Haase and Phillips (2004) identified invisibility concerns of AYAs in research. The authors commented that AYA data are not distinguished from children and adults, and care is rarely received in settings designed to address their unique needs. They concluded future research is required “to determine how philosophy of care, staffing skill and orientation to AYA and other ecological factors influence the implementation of psychosocial studies” (p.146). Research priorities for AYAs’ adjustment to the cancer experience identified by Haase and Phillips (2004) include: the meaning the AYA derived from their cancer experience; identification of psychosocial and developmental models that represent the AYA cancer experience; the sensitivity of existing psychosocial measures to the AYA experience; identification of AYAs concerns and preferred ways to effectively address these concerns; ways to improve provider communication with AYAs; and the feasibility, cost and treatment, and psychosocial outcomes of AYA care. The need to use meaning-based models to understand the AYAs’ experience, an understanding of how AYAs adjust positively to their cancer, and hope and spirituality requires more investigation. Research to describe the illness-related distress; in particular the trajectory of the illness-related distress, efficient interventions and developmental differences is also required. Added to this, are more longitudinal studies and the development of age-appropriate instruments. Finally, further research into uncertainty and research into the different coping strategies used by AYAs are required.

This study is concerned with the experience of family members as they travel the cancer landscape in which their loved AYA lives with, and eventually dies of, cancer. Given
the limited research associated with AYAs and cancer, as identified by Haase and Phillips (2004), it is important to identify and review research which can further our knowledge and provide input into the aims of this study.

Therefore, this chapter examines relevant literature that can increase our understanding of the experience of families who have had an AYA member diagnosed and eventually die of cancer. Publications and related studies were selected to explore, describe and interpret the experience of the cancer journey for an adolescent or young adult and their family, from the time of diagnosis until death. This literature review of 106, articles and books reinforced the invisibility of this group of people and their families. There was limited literature specific to AYAs as defined in this study, and the cancer journey. In addition this literature review found no literature specific to AYAs death and dying.

The literature is organised within the cancer stages identified by Armstrong-Coster (2004) who, through her interviews with people who were dying of cancer and their carers, identified Departure, Exploration, Anticipation and Destination as the stages of the cancer journey. From examining the literature within the Departure, Exploration, Anticipation and Destination stages, three broad areas of concern emerged, life stage issues; psychosocial issues; and health care provision. The Destination stage identified further areas of concern: end of life decision making; place of death; and the dying trajectory.

**Conducting the Literature Review**

The following databases were accessed - CINAHL Plus with full text, ProQuest 500, Expanded Academic ASAP, Google Scholar, PubMed, ProQuest Dissertation & Theses, and Theses-ADT program. The key words and phrases used for the search were: adolescent cancer; teenage cancer; adolescent and young people cancer; psychosocial issues for adolescents with cancer; life stage issues for adolescents and cancer; families and adolescents with cancer; siblings and adolescent cancer; parents and adolescent cancer; nursing care of adolescents with cancer; and death and dying in adolescents. The numbers of articles related to each of the key words were not recorded. As I became more involved with the research, the databases were accessed on numerous occasions throughout the research process and, as I became more engrossed with this process, an accurate record was not kept. The articles of interest were identified by title and the abstracts were read to ascertain whether the information in the article would support the
research study. The full text articles were downloaded or photocopied from the relevant journal. Full text articles that were not available from Southern Cross University databases or journals were obtained through Southern Cross University’s document supply service. Scholarly texts not available in the library were purchased by myself or borrowed through interlibrary loan. As I became more involved with the literature search, further articles were obtained through links to related articles within the database and reference to other articles within the journal article that I was reading.

The selection of literature was based on six broad areas appropriate to the research study, namely: cancer in adolescents and young adults; the experience of cancer; life stage and psychosocial issues for adolescents and young adults with cancer; family issues for adolescents and young adults with cancer; and adolescent and young peoples’ death and dying. The number of articles eventually included in this literature review was 106.

**THE CANCER JOURNEY**

Campbell (1949 reprinted 2008) in his study of world myths exposed a pattern of storytelling that is basically the same story understood in terms of the hero myth. Arthur Frank (1997) introduced this pattern of storytelling as the quest narrative to explain alternative ways of being ill, i.e. the idea of a journey emerging with the development of a sense of purpose for the illness (Frank, 1997). The diagnosis of cancer results in the patient, and those who care for the patient, following a trajectory often referred to as the cancer journey and follows a similar pattern to that described as the quest narrative. This journey is inundated with medical appointments, hospital visits and admissions, possible surgery, chemotherapy and radiation therapy appointments, and dealing with the physical and psychosocial effects of the treatment. Mathiesons and Stam (1995) comment on the difficulties that patients experience in dealing with institutionalised medicine and the organisation of their social world within this medical system. The patient with cancer is confronted with dynamic psychosocial events. “These events often result in reports of loss of productive functioning, financial strain, family stress, personal distress, stigma, and threats to former self images. Taken together, these events signal that one’s identity will forcibly undergo transformation” (Mathieson & Stam, 1995, p.287).
This is reinforced by Armstrong-Coster (2004) and Costain Schou and Hewison (1999) in the following studies and accounts of the cancer journey.

Armstrong-Coster (2004) conducted an ethnographic study of people who were dying of cancer and their carer’s, in her book *Living and Dying with Cancer*, and she selected the narrative of 12 people in the UK that to her best captured the dying experience. The narratives were obtained from longitudinal, in-depth interviews from patients and their carers throughout their dying trajectory. From her research she has identified four stages common to those who live and eventually die of cancer, see Table 2.1. These stages are similar to Franks’ hero’s journey with the exception that the hero does not return.

**Table 2.1  The Four Stages Common to Those who are Dying From Cancer**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Departure</strong></td>
<td>The time of detecting initial symptoms and learning their diagnosis</td>
</tr>
<tr>
<td><strong>Exploration</strong></td>
<td>The time of tests and treatment</td>
</tr>
<tr>
<td><strong>Anticipation</strong></td>
<td>The time of remission and fear of recurrence</td>
</tr>
<tr>
<td><strong>Destination</strong></td>
<td>The time when the imminence of death could not be denied</td>
</tr>
</tbody>
</table>

Armstrong-Coster (2004, p.3)

Costain, Schou and Hewison (1999) in the *Facing Death Series ‘Experiencing Cancer: Quality of Life in Treatment’*, obtained the material for the text through a qualitative study of the treatment experience of a heterogeneous group of 44 cancer patients undergoing radiotherapy and/or chemotherapy in a large regional treatment centre in the North of England; some of these patients were also receiving chemotherapy in a district hospital about 45 minutes away from the regional centre. The authors used grounded theory as a methodology and conducted semi-structured interviews with constant comparison as the method of analysis. This resulted in the construction of an illness and treatment calendar to provide an explanation of the cancer journey. This illness and treatment calendar revealed a severe disruption to the patient’s life calendar. This disruption resulted in a disturbance in future plans “plans related to achieving goals,
work achievements, relationships and the calendar of day to day living” (Costain Schou & Hewison, 1999, p.49).

Each of the stages identified by Armstrong-Coster (2004) and the illness and treatment calendars described by Costain Schou and Hewison (1999) identified that families and patients are presented with unique medical, emotional and psychosocial difficulties. These difficulties are further intensified according to the life stage of the patient. This is particularly true for AYAs, with a severe disruption of their future goals and plans.

**THE AYA CANCER JOURNEY**

The AYA with cancer journey follows a similar trajectory to those described by Armstrong-Coster (2004), and Costain Schou and Hewison (1999). In addition, the AYA with cancer is required to negotiate the primary developmental changes of adolescence within an interpersonal context that is influenced by intrapersonal moderating variables (Holmbeck & Shapera, 1999).

O’Connor (2006), in his Report on non-physical interventions to improve outcomes for adolescents and young adults with cancer in Australia, identified physical, emotional and social effects of the cancer journey. The patients in this Report rated the emotional, functional and social effects as having a greater impact on the quality of life than the physical. The effects include distress, which includes depression and anxiety, and functional and social impairment. In addition, the patient experiences fear that the cancer may spread, anxiety with regard to the chemotherapy or radiation therapy, self consciousness about appearance, general loss of confidence, feelings of fragility and insecurity, feelings of being a burden to others, and sexuality issues. Support from family and friends was a source of comfort, although the cancer experience can result in a distancing from family and friends. Other researchers have found that financial burden is also a stressor (Owen, et al 2001; Jefford, et al 2005; Lintz, et al 2003, Verde, 2004 as cited in O’Connor 2006).

Despite identification of these physical, emotional and social effects of the AYA cancer journey, there is limited research on AYAs and cancer. For example, O’Connor’s (2006) Report was mainly based on studies of children and adults because of limited research with this forgotten population. Michelagnoli, Pritchard and Phillips (2003) described AYAs as a lost tribe, a group whose unique needs have been neglected. The identification of these needs has been minimal until the end of the 20th Century
(Whiteson, 2003). Palmer, Mitchell, Thompson and Sexton (2007) indicate that throughout the world there is now recognition that the needs of this particular group of people are not being met within either the paediatric or adult health system. At present there is little known about the physical or social needs of this patient group (Palmer et al 2007).

The next section introduces literature that provides a deeper understanding of life stage and psychosocial issues for the AYA and the family, in addition to literature on the health care provision for this forgotten group of people. These concepts will be discussed within the Departure, Exploration and Anticipation stages of the cancer journey, as identified by Armstrong-Coster (2004).

Within this context it should be noted that life stage, psychosocial, and health care provision associated with the AYA cancer journey are not mutually exclusive, with many of the issues influencing each other and overlapping. As a result, many of the studies discussed more than one issue associated with the AYA and the AYA’s family members’ cancer journey. The issues identified above also have relevance to the Destination stage of the cancer journey. Although, this stage of the cancer journey has other specific issues, namely End of Life (EOL) decision making, place of death and the dying trajectory, these specific issues and the associated literature will be discussed separately in this chapter. The literature associated with life stage, psychosocial, and health care provision for AYAs and family members is organised chronologically in Table 2.2. and spans the years 1985-2010.
<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Study</th>
<th>Areas</th>
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</thead>
<tbody>
<tr>
<td>2010</td>
<td>Zebrack, Chelser, &amp; Kaplan</td>
<td>Focus groups of AYA cancer survivors to discuss what people said or did which they found helpful or hurtful</td>
<td>Psychosocial Healthcare provision</td>
</tr>
<tr>
<td>2009</td>
<td>Yeo &amp; Sawyer</td>
<td>Scholarly article on psychosocial framework for the assessment of AYAs with cancer</td>
<td>Health care provision</td>
</tr>
<tr>
<td>2008</td>
<td>Carlsson, Kihlgren &amp; Sorlie</td>
<td>Phenomenological study on the experience of suffering and enduring for adolescent girls with cancer</td>
<td>Life stage Psychosocial</td>
</tr>
<tr>
<td>2008</td>
<td>Zebrack</td>
<td>Quantitative online survey of AYAs and diagnosed with cancer to identify supportive care needs</td>
<td>Psychosocial Health care provision</td>
</tr>
<tr>
<td>2008</td>
<td>Patterson, Millar &amp; Desille</td>
<td>Survey to examine the unmet needs of AYAs who have or have had cancer</td>
<td>Lifestage Psychosocial Health care provision</td>
</tr>
<tr>
<td>2008</td>
<td>Woodgate</td>
<td>Descriptive qualitative research of children interpretation of cancer symptoms</td>
<td>Psychosocial</td>
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<tr>
<td>2008</td>
<td>Corey et al</td>
<td>Cross sectional study of AYAs with cancer of relationship between social support and symptom distress</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2008</td>
<td>Cassano, &amp; Nagel</td>
<td>Descriptive study of adolescents with cancer to explore adolescent's perception of peer support</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2008a</td>
<td>McGrath &amp; Phillips</td>
<td>Part of a longitudinal study on the treatment experience for families of children with blood cancer which examined the parents perspective of the children response to treatment</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2008b</td>
<td>McGrath &amp; Phillips</td>
<td>Part of a longitudinal phenomenological study of families with childhood cancer which examined the father perspective</td>
<td>Psychosocial</td>
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<tr>
<td>2008</td>
<td>McGrath</td>
<td>Part of a longitudinal phenomenological study of families with child hood cancer examining parents perspective of the effect on siblings</td>
<td>Psychosocial</td>
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<tr>
<td>2008</td>
<td>Patterson, Millar &amp; Vissar</td>
<td>Research into the unmet needs of siblings of young people with cancer</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2007a, 2007b</td>
<td>Grinyer</td>
<td>Narrative study of AYAS to explore the experience of a young person living with cancer</td>
<td>Delay in diagnosis Life stage Psychosocial Health care provision</td>
</tr>
<tr>
<td>Year</td>
<td>Author</td>
<td>Study</td>
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<tr>
<td>2007</td>
<td>Decker, Haase &amp; Bell</td>
<td>Cross sectional comparative survey of adolescents with cancer to describe uncertainty in the cancer experience</td>
<td>Psychosocial</td>
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<td>Health care provision</td>
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<tr>
<td>2007</td>
<td>Miedema, Hamilton &amp; Easley</td>
<td>Grounded theory study on the psychological impact of young adults diagnosed with cancer</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2007</td>
<td>Clemente</td>
<td>Ethnographic study of AYA cancer patients and clinicians to observe information disclosed</td>
<td>Health care provision</td>
</tr>
<tr>
<td>2007</td>
<td>Palmer, Mitchell and Sexton</td>
<td>Grounded theory using focus groups of adolescent cancer patients to identify unmet needs</td>
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<tr>
<td>2007</td>
<td>O’Connor</td>
<td>Report non physical interventions to improve outcomes AYA’s living with cancer</td>
<td>Life stage issues</td>
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<td>Psychosocial</td>
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<td>Health care provision</td>
</tr>
<tr>
<td>2006</td>
<td>Miedema, Easley &amp; Hamilton</td>
<td>Qualitative study using semi-structured interviews to examine the experience of cancer in adults 20-35 years</td>
<td>Delay in diagnosis</td>
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<td>Larouche &amp; Chin-Peuckert</td>
<td>Semi structured interview of adolescents with cancer perspective of their body issues</td>
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<td>Psychosocial</td>
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<td>2006</td>
<td>Evan &amp; Zelter</td>
<td>Literature review of the psychosocial dimension of AYAs with cancer</td>
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<td>2006</td>
<td>Fochtman</td>
<td>Concept analysis of suffering</td>
<td>Psychosocial</td>
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<td>2006</td>
<td>Thomas, Seymour, O’Brien, Sawyer, and Ashley</td>
<td>Overview of issues associated with AYAs with cancer</td>
<td>Psychosocial</td>
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<tr>
<td>2006a</td>
<td>Woodgate</td>
<td>Part of a longitudinal study of adolescent cancer patients explored the degree and type of social support for adolescents with cancer</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2006b</td>
<td>Woodgate</td>
<td>Part of a longitudinal study to examine the experience childhood cancer from the child and their family’s perspectives</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2006</td>
<td>Zebrack, Bleyer, Albritton, Medearis &amp; Tang</td>
<td>Delphi survey of oncology health care professionals and young adults diagnosed with cancer to identify health and supportive care needs for AYA patients and survivors</td>
<td>Life stage issues</td>
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<td></td>
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<td>Health care provision</td>
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<tr>
<td>2006</td>
<td>Mitchell, Clarke &amp; Sloper</td>
<td>Postal survey of 506 families in paediatric treatment centres provides an overview of the care and psychosocial support for children young adults and their families</td>
<td>Lifestyle</td>
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<td>Health care provision</td>
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<td>2006a</td>
<td>Grinyer</td>
<td>Narrative analysis the mother health who has a young person with cancer</td>
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<td>Year</td>
<td>Author</td>
<td>Study</td>
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<td>Book chapter describing the long term psychosocial consequences of teenage cancer</td>
<td>Life stage issues Psychosocial</td>
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<td>Wallace &amp; Broughham</td>
<td>Literature Review on sub fertility in adolescents with cancer</td>
<td>Life stage issue Psychosocial</td>
</tr>
<tr>
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<td>Neville</td>
<td>Qualitative inquiry using grounded theory to determine the impact on adolescent development for survivors of childhood cancer</td>
<td>Life stage Psychosocial</td>
</tr>
<tr>
<td>2005</td>
<td>Woodgate</td>
<td>Part of a qualitative longitudinal study researched possible changed sense of self with adolescent cancer patients</td>
<td>Life stage</td>
</tr>
<tr>
<td>2005</td>
<td>Herbertson &amp; Hancock</td>
<td>Examined the psychosocial effects of adolescents with Hodgkin lymphomas as part of a scholarly article on adolescents with Hodgkin’s lymphoma</td>
<td>Psychosocial effects Health care provision</td>
</tr>
<tr>
<td>2005</td>
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<td>2004</td>
<td>Zebrack &amp; Walsh-Burke</td>
<td>Survey and focus group of paediatric oncology social workers to examine the advocacy needs of AYAs with cancer</td>
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<td>2004</td>
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<td>2004</td>
<td>Epstein, Orr &amp; Stevens</td>
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<td>McGrath &amp; Huff</td>
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<td>Examined the process of restructuring self of adolescent cancer patients through narrative</td>
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<td>Spinetta Jankovic &amp; Eden</td>
<td>Guidelines for the assistance to siblings of children with cancer</td>
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<td>1998</td>
<td>Neville</td>
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<td>Quantitative study on the emotional impact of the diagnosis of cancer in adolescents in families</td>
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<td>1996</td>
<td>Brown &amp; Barbarin</td>
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<td>Mathieson &amp; Stam</td>
<td>Grounded theory approach which identified identity transformation as a result of the cancer diagnosis</td>
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<td>Nicholas</td>
<td>Scholarly article on social support and coping in adolescents with cancer</td>
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<td>1995</td>
<td>Dunsmore &amp; Quinn</td>
<td>Descriptive exploratory study to identify the support and information needs of AYAs living with cancer</td>
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<td>1985</td>
<td>Tebbi, Stern, Boyle, Mettlin &amp; Mindell</td>
<td>Interview to evaluate the relationship between post surgical adjustment and social support for AYA cancer amputation patients</td>
<td>Psychosocial</td>
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DEPARTURE STAGE

Delayed Diagnosis

Armstrong-Coster (2004) speaks of this stage of the cancer journey as a boundary marker away from the life they had previously lived into the unfamiliar cancer landscape. Interestingly, despite the huge impact a cancer diagnosis would have on the AYA and their family, the literature had limited studies on this stage of the cancer journey. The literature mainly referred to problems concerning delays in diagnosis associated with the life stage issues for an AYA.

The cancer journey begins with the diagnosis. Canadian research (Miedema, Easley, & Hamilton, 2006) which explored the experience of cancer in adults aged 20-43, six men and nine women diagnosed between 20-35 years, identified that for young people with cancer there is often a delay in diagnosis. This delay was reported by the patients to be associated with a sense of invincibility, interpreting the symptoms as lifestyle choices, ignoring the symptoms due to fear of a serious illness or a re-occurrence of the cancer, and a shortage of family physicians. From the physicians’ perspective, some were reluctant to make a diagnosis of cancer while others believed the symptoms could not be cancer because of the person’s age. The authors concluded that this delay in diagnosis contributed to added stress in an already stressful situation. This study did not include the younger AYA and there may be other factors associated with this age group.

This is in contrast to Grinyer’s grounded theory (2007a, 2007b) UK study. The study through storytelling, explored the experience of a young person living with cancer aged 16-26 years. Grinyer used in-depth interviews with 29 AYAs diagnosed with cancer 24 were from two hospital Trusts – 12 from a specialist adolescent unit, and 12 from one general oncology ward, in addition to five written transcripts. This study found, whilst there was a sense of disbelief when the AYA was diagnosed with cancer, this was not as a result of the AYA not seeking medical advice. It was more related to accepting the advice from a medical professional that the symptoms were not serious. Grinyer (2007a) believes this is related to the life stage of the AYA and the medical professional interpreting the symptoms within the context of the most probable diagnosis for this age group, augmented with concern about subjecting the AYA to what may be unnecessary, distressing and expensive tests. Grinyer’s (2007b) article found more rapid diagnosis was made with the presentation of more common cancers, if the AYA is informed and
aware, if the physician has dealt with similar cancers before and if the AYA presents to an Accident & Emergency department.

The literature reviewed found no research on the impact of the Departure stage for an AYA and the AYA’s family. The majority of the literature is reported in the next stage of the cancer journey, the Exploration stage. This represents the cancer journey after the initial diagnosis and the tests and treatment within this landscape. As mentioned previously, AYA issues in the Exploration stage are also significant for the Destination

**EXPLORATION STAGE**

The Exploration stage of the cancer journey is a time of test and treatment. Armstrong-Coster (2004) describes this stage as learning to adapt to the cancer landscape and changes in social relationships. For the purpose of this literature review the information is organised according to life stage, psychosocial, health care provision and family issues.

**Life Stage Issues**

With respect to life stage issues and the cancer journey in AYAs, the relationship with parents and siblings, achieving independence, identity formation, self concept and body image, education and career aspirations, social life, relationship with peers, isolation, information, support, sexuality, the development of intimate relationships, fertility, and hopefulness are documented as major challenges by a number of researchers (Ettinger & Heiney, 1993; Harvey & Finch, 2008; Ritchie, 1992; Canadian Paediatric Society., 2006; Suris, Michaud, & Viner, 2004; Veach, Nicholas, & Barton, 2002; Whyte & Smith, 1997 2006).

Self’s (2005) book chapter, *Surviving the scars: the long-term psychosocial consequences of teenage cancer*, identified the following life stage issues which are associated with AYA and cancer:

*Control*: the major physical, social and emotional changes of adolescence can result in a sense of lack of control; cancer treatment involves further changes such as radical surgery, hair loss, fatigue and sexual changes representing a frightening loss of control.
**Self-esteem:** The side effects of cancer treatment such as hair loss, weight changes and surgical procedures can create negative changes in body image, with a lowering of self-esteem, which can persist for decades.

**Identity:** the diagnosis of cancer can result in the potential loss of a new found identity. “To lose both remembered past and hoped for future before discovering who one really is presents an intolerable confusion” (Self, 2005, p. 184).

**Independence:** the diagnosis of cancer results in the AYA regression to a former developmental stage as the AYA becomes more dependent on parents and caregivers. The AYA has to contend with hospitalisation, invasive treatments and at times is unable to perform the intimate tasks of daily living that can be a source of resentment and anger.

**Communication:** the development of adult communication patterns may be delayed and difficulty in communication patterns may be accentuated. The adolescent may keep his concerns and problems to himself.

**Relationships:** adolescence is a period when peer groups and relationships are of importance. The cancer journey threatens these peer group relationships, Hospital visits, prolonged treatment, and frequent absences from school and lowered self esteem can lead to anxiety, and isolation. In addition peers are confronted with their own views on mortality and may withdraw from the AYA.

Grinyer (2002a, 2008) conducted a narrative correspondence study of the parents’ experiences of having an AYA son or daughter living with cancer. Twenty eight participants were recruited via the palliative care network in the UK, through an appeal of a mother whose son had died of cancer. The study provided insights into life stage issues of young people with cancer and also addressed the topic of bereavement if the young person died. Grinyer identified the following life stage concerns: the effect of an unwilling return to an earlier dependent life stage; the ambiguity surrounding sharing information with parents about the cancer and its treatment; and the sharing of delicate information, such as sexuality and fertility, usually kept private or discussed with peers.

These life stage issues are compounded by the toxicity of the cancer treatment documented in Bleyer’s (2002) literature review on AYAs with cancer. Bleyer’s review cited the acute and delayed toxicities of cancer therapy as among the worst associated
with chronic disease. Added to this is the distinct possibility of infertility, as reported by Wallace and Brougham (2005) in their review of the literature on subfertility in adolescents with cancer.

The following literature uncovers, in more detail, specific life stage issues for AYAs living with cancer: identity formation; normalcy; body image; and sexuality.

**IDENTITY FORMATION**

Research has found that the diagnosis of cancer in an AYA has the ability to delay the developmental task of identity formation (Carlsson, Kihlgren, & Sorlie, 2008; Epstein, Orr, & Stevens, 2004; Mathieson & Stam, 1995; Neville, 2005; Ritchie, 1992; Zebrack & Walsh-Burke, 2004).

Mathieson and Stam’s (1995) Canadian study used a grounded theory approach and open-ended interviews to examine the stories of 37 heterogeneous cancer patients: 11 males and 26 females, to reframe the psychosocial issues of cancer as one of identity altering. They argue that the psychosocial events associated with cancer will result in an identity transformation and a re-evaluation of one’s life story. Further to this, Zebrack and Walsh-Burke’s (2004) qualitative and quantitative study recruited 55 North American paediatric oncology social workers to complete a survey and, of those, a further 14 took part in a focus group. The purpose of the survey and focus group, was to identify the advocacy needs of adolescents and young adult cancer survivors. One of the findings from this study was the AYAs’ concern about the effects of cancer treatment that had an influence on the developmental task of identity and socialisation with peers.

The narratives of Grinyer’s (2007a; 2007b) grounded theory study on the experience of AYAs with cancer, verified an interruption in their life trajectories at a critical transitional life stage. This interruption resulted in distinct difficulties for this group of people, with chronic biographical effects. This finding is reinforced by a narrative study by Sunmi Lee (2001) of three stories from one young cancer survivor, which demonstrated how the experience of having cancer as a young person influenced the participant’s development. The stories spoke of how her peers reacted to her illness and her struggle to understand the illness. The diagnosis of cancer was seen as not being part of the dominant narrative of what it is like to be young, and the participant’s dilemma of whether to incorporate the cancer experience as part of her future identity.
This dilemma is elaborated in Woodgate’s (2005) Canadian study. Woodgate researched the possibility of a changed sense of self from the cancer experience with 15 adolescent cancer patients aged 12-18 years. The findings of this research confirmed that the adolescent felt different with a dynamic changing sense of self, but basically they believed they were the same person who occasionally wanted to be treated as special. This is affirmed by Kameny & Bearison’s (1999) North American study. These researchers examined the process of reconstructing self of three adolescent cancer patients (aged 14, 16 and 17) through narrative. They discovered that although the prognoses and coping methods differed, the participants attempted to maintain their sense of self in the midst of the cancer experience across three domains; personal, biomedical and social. Alternatively, Kihlgren and Sorlie (2008) found the adolescent girls in their qualitative phenomenological study, referred to in more detail when discussing suffering in this chapter, believed they were different to others and to what they were before. As these studies were small, it is difficult to determine if there is a gender difference in the sense of self experienced by adolescent cancer patients.

This impact of cancer on identity formation is given further credence by Neville (2005) who conducted an in-depth qualitative inquiry of young adult survivors of childhood cancer, using grounded theory. The long term follow up group, from a childrens cancer centre in the North east corner of the US, involved six females and one male aged 23-30 years. The study sought to determine the impact of surviving cancer on adolescent development. Catching up socially was seen as being the most difficult, having lost the opportunity in adolescence for the formation of peer groups and the development of intimacy. Many participants described isolation and loss of friends over time due to the fact they lost the opportunity to engage in normal social activities. Stigma as an adolescent with cancer was also an issue. Whilst this study revealed that the cancer experience interfered with normal developmental tasks, it also had the effect of increasing the AYA’s level of maturity and ability to contemplate the bigger questions in life.

NORMALCY

An overriding theme that was present in the literature on the cancer journey, was the AYA’s desire to be normal despite the effects of cancer and its treatment. An overriding goal was a return to normal at the end of treatment (Decker, Haase, & Bell, 2007; 2004; Evan & Zeltzer, 2006; Miedema, Hamilton, & Easley, 2007; Patterson, Millar, &
Desille, 2008a). Woodgate’s (2000) review of qualitative research to increase the understanding of children with cancer, identified this attempt to be normal, where children and adolescents created a new normality for themselves which incorporated the cancer experience. Those children unable to engage in normal activities experienced a sense of isolation. However, Woodgate’s review included children and adolescents and excludes young adults, who are a part of this study. However, the following study supports Woodgate’s (2000) review and includes adolescents and young adults.

Grinyer and Thomas’s (2001) and Grinyer (2002a) narratives of parents of young adults in the UK with cancer aged 18-25 years, examined the effects of cancer on parents and family when a young person has cancer. These authors found sustaining normality a close second to independence as a major theme. These researchers found an attempt to be normal was made more problematic due to the transitional phase in the person’s life, with friends moving on and establishing themselves. Normality was experienced in returning to study or work, often when they were not well enough. This attempt to be normal is compounded by the AYA’s loss of physical (Grinyer, 2002a, 2007a) and at times financial independence (Grinyer, 2007a) as a result of the cancer experience. The loss of physical independence can result in a renewal of infantile dependence, which is perceived as a retrograde step and may interfere with the AYA’s attempt to be normal (Grinyer, 2002a, 2007a). The desire to be independent and to engage in normal behaviour had the potential to create tension between parents and young people, with parents at times finding it difficult to stand back and watch the AYA engage with what they perceived to be ‘at risk’ behaviours and the AYA’s finding this concern stifling (Grinyer, 2009).

**BODY IMAGE**

The diagnosis of cancer and the effects of treatment have an impact on the AYA’s perception of self and body image (Self, 2005) that can have psychological consequences (Evan & Zeltzer, 2006; Grinyer, 2002a, 2007a, 2008; Grinyer & Thomas, 2001; Larouche & Chin-Peuckert, 2006; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). In Grinyer’s (2007a) UK narrative study of AYAs with cancer, the AYAs spoke of the profound effect that the physical changes of the cancer treatment had on their morale and self-confidence. Appearance was seen as central to belonging, with many
fearing rejection, that had the potential to result in social isolation. This is affirmed by Larouche and Chin-Peuckert’s (2006) Canadian study. These researchers conducted semi-structured interviews with five adolescents with cancer, aged 12-18 years, in order to explore their perspectives of their body image when faced with cancer and its treatments and how this perceived body image impacted on their everyday life. The adolescents had a negative body image as they perceived themselves to look different, unattractive and sick which aroused feelings of vulnerability. The way they coped with these feelings of vulnerability impacted on their life to the extent that some would avoid social situations; they would attempt to hide the changes to the body caused by the cancer experience, and, they relied on friends to act as protectors as they gradually returned to their social life.

**SEXUALITY**

Sexuality, and in particular information about sexual and intimate relationships and future fertility and how the cancer influences this, was seen as an important need of AYAs (Decker, et al., 2004; Grinyer, 2002a, 2008; Grinyer & Thomas, 2001; Palmer, et al., 2007; Patterson, et al., 2008a; Whyte & Smith, 1997; Zebrack, 2008; Zebrack, et al., 2006; Zebrack & Walsh-Burke, 2004). Despite the importance the AYAs placed on sexuality issues or future fertility, these issues were raised by the young person or the parent and rarely brought up by the medical staff (Palmer, et al., 2007). Consequently AYAs talked to their parents about sexual matters, such as lack of sexual experience, the demise of intimate relationships, the prospect of never having a sexual relationship, and fertility and sperm donation (Grinyer, 2002a, 2008; Grinyer & Thomas, 2001).

**Psychosocial Issues**

Evans and Zelter’s (2006) literature review summarised what is known regarding the psychosocial dimension of cancer in adolescents and young adults. They discovered that psychological, emotional and social factors differed according to the developmental stage of the adolescent and the stage of treatment. The authors concluded that significant weight should be placed on examining the developmental levels and stage of treatment when researching AYAs with cancer. This section of the literature review
focuses on those studies that provide a deeper understanding of psychosocial issues which effect AYAs with cancer and their families.

Whyte & Smith’s (1997) literature review on adolescents and cancer discovered the following recurring issues related to AYAs living with cancer: parents and siblings; psychosocial issues; school and social life; information and support; sexuality; and hopefulness. Added to this, Woodgate (2000b) conducted a critical review of the qualitative research that related to children’s experiences with cancer. She discovered the cancer experience hurts children and adolescents, through pain associated with the procedures, fatigue, fear of relapse, isolation from friends and family, loss of irreplaceable time, fear of dying and feelings of powerless (Woodgate, 2000b). This review included younger adolescents and children; young adults were not included although the review highlights issues which are useful to this study for comparison.

On the other hand Zebrack’s (2008) online survey, of 217 young adults aged 18–40 years in North America, reported that many supportive care needs and preferences for young people with cancer are not being met. He concluded that “health status and physical functioning may be associated with the extent to which these needs are being met” (Zebrack, 2008, p. 1359). The age group in Zebrack’s (2008) study includes adults and AYAs and Woodgate’s (2006b) review includes children and AYAs. Therefore, both studies have included AYAs within a larger cohort where the experience and issues specific to AYAs can be subsumed, although the studies do lend support to issues for this group not being addressed.

The previous literature provides a broad overview of psychosocial issues related to the AYAs’ cancer journey. For the purpose of the cancer journey for AYAs, the following subjects have been identified as major psychosocial issues: psychological problems; suffering; uncertainty about the future and survivorship; coping strategies; and social support.

**Psychological Problems**

The diagnosis of cancer results in a variety of psychological issues for the AYA to contend with, which would result in psychological distress for the AYA. Although, Neville (1996) in her descriptive study to measure the psychological distress among middle and late adolescents recently diagnosed with cancer, 40 males and 20 females aged 14-22 receiving outpatient treatment in two regional cancer centres in Northeast
America, found no significant difference in psychological distress between adolescents with cancer and the healthy adolescent population.

This was also evident in Allen, Newman and Souhami’s (1997) UK longitudinal quantitative study, which studied the emotional impact of the diagnosis of cancer in 42 adolescent patients and their families, 34 mothers and 27 fathers. In the first stage of this study recently diagnosed adolescents (three weeks) and their parents completed the Beck Depression Inventory and Spielberger’s State Trait Anxiety questionnaire. The results demonstrated that adolescents with cancer were no more depressed or anxious than adolescents without cancer. However, Neville (2005) argues that the instruments used measure psychopathology and most adolescents do not demonstrate psychopathological symptoms; the cancer experience is demonstrated in other behaviours as they are confronted with a significant life stress, such as school phobias, separation anxiety and features of non-compliance.

Allen, Newman and Souhami’s (1997) initial report occurred only three weeks after the AYA had been diagnosed with cancer, when the patient and family first presented for treatment and as such the participants had only just begun exploring the cancer landscape. In contrast, Patterson, Millar & Desille’s (2008) Australian study which examined the needs of 112 young people who have or have had cancer, aged 12-24 years, identified the emotional psychological domain as the most salient unmet need in dealing with cancer. The cohort participants in this study were not newly diagnosed and were members of CanTeen, with some having survived the cancer journey. These unmet needs included: help with dealing with feelings of distress; sadness; fear; frustration anxiety about possible side effects; and uncertainty about the future (Patterson, et al., 2008a). For the participants in this study the AYAs’ psychological function scores were not elevated. Although 30% of the 12-17 year olds showed clinically elevated total difficulties score, using Goodman’s Strength and Difficulty Score as a measure, and 25% of the 28-24 year olds had clinically elevated depression and anxiety scores using Lovibond & Lovibond’s Depression and Anxiety Scale as a measure. These scores were correlated with unmet need. The report identified additional unmet needs, for the 18-25 year olds, as transition and autonomy, residual trauma, and existential, or a need to find meaning and purpose in life and to make a positive contribution to the world in some way (Patterson, et al., 2008a). This study supports Woodgate’s (2006b) and Zebrack’s (2008) studies mentioned previously where, despite the cohorts including children in
Woodgate’s study and older young people in Zebrack’s study, there are identified concerns in the care of AYAs with cancer.

**SUFFERING**

Authors such as Fochtman (2006), Epstein, Orr and Stevens (2004), Neville (1998) Woodgate (2008) and Carlsson, Kihlgren and Sorlie (2008) have described the cancer journey for children and adolescents as suffering. Suffering has been defined by Morse as two major behavioural states “enduring (in which emotions are suppressed; it is manifest as an emotionless state) and emotional suffering (an overt state of distress in which emotions are released)” (Morse, 2001, p. 47). Not all the authors adopted Morse’s definition of suffering, with Woodgate (2008) accepting it as an undefined concept, and Fochtman (2006) suggesting more research to understand the true nature of suffering.

Epstein, Orr and Stevens’ (2004) qualitative meta-synthesis of 17 articles which focussed on the experience of suffering and endurance in children and adolescents with cancer aged 5-21 years, revealed five different concepts which affected the adolescents’ and children’s degree of suffering with respect to the cancer journey. These concepts included: how information was communicated by health care professionals to parents and themselves; and the experience of loss (loss of body, loss of life, loss of body parts, loss of relationships, loss of mental capacity, loss of time, and loss of place at home). The authors found this resulted in enduring the suffering or suppressing one’s emotions. Three types of enduring were recognised: enduring to survive; enduring to live; and enduring to die.

Whilst enduring, the adolescents’ and children’s struggle for normalcy was difficult because the suffering was always present. The children and adolescents sought ways to deal with this suffering and endurance, in which meaning was given to the cancer experience and evidenced by a changed identity with a more philosophical perspective and maturity. This was also evident in the literature on identity formation in this study. Although once again Epstein, Orr and Stevens’ review included articles where children were as young as five, it could therefore be questioned as to whether it provides a true representation of the experience for an AYA.

A Swedish phenomenological study by Carlsson, Kihlgren and Sorlie (2008) examined this experience of suffering and enduring by exploring the concept of fear in adolescent
girls no longer under active treatment, (n) 6 aged 14-16 with a personal experience of cancer. Their fears related to fears concerning the physical body as a result of cancer and its treatment, existential fears, particularly in relation to the uncertainty of the cancer journey, and fears in relation to their changed social self. However, the study did not include the lived experience of young males and included a younger adolescent cohort.

Woodgate’s (2008) interpretive, descriptive Canadian study, of 13 children aged 9-17 years, described and interpreted what children and adolescents think and feel about their cancer symptoms. Woodgate found that all participants accepted that suffering was part of their journey. This suffering is personified with the following meaning: ‘cancer is threatening, numbing, uncontrollable and unruly, painful and uncertain.’ The participants remembered these feelings and tried to avoid situations and things that reminded them of this. Once again the older AYA is excluded in this study with the youngest in the group aged nine and the oldest 17. Thus the cohort from 18 to 25 experience of suffering was not explored. Despite the issues with the age of the cohorts and the specific gender, these three studies of suffering revealed that suffering profoundly influences the meaning AYAs derive from the cancer journey.

Fochtman (2006) conducted a concept analysis of 200 references from nursing, medicine, social work, psychology, ethics and religion which included suffering or distress for children with cancer as a central theme. Fochtman (2006) concluded suffering needs to be defined and measured by self-report to gain an accurate, complete and holistic picture of the nature and scope of the child’s and adolescent’s suffering. Further research is required on the lived experience of children and adolescents with cancer, to determine their distress and suffering. From the perspective of this current study, further research should also include AYAs experience of suffering.

**Uncertainty About the Future and Survivorship**

A major theme occurring in the literature reviewed was survivorship and uncertainty about the future (Carlsson, et al., 2008; Decker, et al., 2007; Decker, et al., 2004; Neville, 2005; Palmer, et al., 2007; Patterson, et al., 2008a; Woodgate, 2008). This uncertainty has been described by Neville as the ‘Damocles syndrome’ expressed as the fears, anxieties, preoccupation with bodily function, and obsessive concern about the progress of the disease (Neville, 2005). Decker, Haase and Bell’s (2007) North
American cross-sectional comparative survey of 193 adolescents with cancer aged 11-22 years, describes uncertainty in the cancer experience, and found that newly diagnosed AYAs had higher uncertainty on several items. These items include future pain; the unpredictability of the illness; staff responsibilities and whether they could care for themselves. On the other hand, adolescent cancer survivors five years since treatment had higher uncertainty on items concerning how the illness affects their life, the predictable success of treatment, predicting the length of the illness and having a lot of unanswered questions. All the survivors indicated higher uncertainty about the multiple meanings of communication with doctors, which highlighted the need for effective communication and clarification from health care providers that would enable AYAs to understand the information they have received. This uncertainty can increase psychological distress, as seen in Neville’s (1998) North American descriptive correlation study that examined the influence of uncertainty and social support on psychological distress. This study found adolescents who reported high levels of uncertainty and low levels of social support, had the greatest psychological distress.

**Coping Strategies**

The ability to manage the psychological impact of a cancer diagnosis and treatment is dependent on how the AYA handles these stresses. Evans & Zelter’s (2006) North American study of six women and nine men cancer survivors aged 20-43, maintained that a young person’s coping skills and strategies are deeply embedded in the young person’s pre-cancer life. Alternatively, Ritchie’s (1992) literature review on the psychosocial functioning of adolescents with cancer, from a developmental perspective, suggested the major coping skills for adolescents with cancer are denial, rationalisation and hopefulness. Her review also revealed that adolescents with cancer used external locus of control as a means of coping with the cancer. Allen (1997) has suggested that this external locus of control, or sense that there is no control of the cancer experience, results in a negative psychological adaptation (Allen, 1997). Evans and Zelter (2006) suggest that being empowered to make decisions and have access to knowledge may increase the adolescent’s internal locus of control.

This is reinforced by Miedema, Hamilton and Easley’s (2007) Canadian grounded theory study on the psychological impact of the diagnosis of cancer on young adults, which included six men and nine women cancer patients and survivors aged 20-43. The study revealed coping skills were enhanced by the information received. During
treatment the participants in the study used problem solving techniques to take action and stay in control of the cancer experience. Others factors which influenced the young person’s coping skills included the physical hardships they endured; the interaction with others around the cancer; and their reflections on the experience (Miedema, et al., 2007). Kynagäs’s (2001) qualitative study, conducted in Japan, used semi-structured interviews to identify the coping strategies of 14 young people with cancer, aged 16-22. The study found accessing information was an important method of coping as well as belief in recovery and in one’s own resources. The spiritual dimension was also seen as a coping strategy (Kyngas, et al., 2001; Nicholas, 1995), as was relaxing.

**SOCIAL SUPPORT**

Miedema, Hamilton and Easley’s (2007) study demonstrated that the young people with cancer were dependant on their existing social networks for support. Woodgate (2000) emphasised, in particular, the support from family and peers. Nicholas’ (1995) article on social support and coping in young adolescents with cancer, reported that the amount of perceived social support for adolescents with cancer was high. As part of Woodgate’s (2006a) Canadian longitudinal study, she explored the degree and type of social support of 15 adolescent cancer patients aged 12-18. Woodgate identified that the three main supportive relationships in the adolescent’s life included the: nuclear family, special health care providers and special friends. Support was provided through the supportive relationships; the person’s psych-emotional presence; and being there to comfort and reassure them throughout the cancer journey. This psych-emotional support, such as handholding and being there, was found to decrease treatment-related pain (Ritchie, 2001). Ritchie’s (2001) North American descriptive study of 45 adolescents diagnosed with cancer, identified mothers as being the person most likely to provide this psych-emotional support.

This was confirmed by Tebbi et al (1985) North American study that interviewed AYA cancer amputees to identify AYAs’ perception of social support at the time of the amputation. The 27 AYAs aged 14-37 years had undergone an amputation at age 11-23. The findings identified parents, particularly mothers, as being the most supportive at the time of surgery for a leg amputation, whilst siblings and health care professionals were also considered supportive. In this study fewer than 50% considered friends to be helpful as the friends felt uncomfortable talking about the surgery and, although they provided some support, they eventually drifted away because of the illness and
subsequent surgery. This is contrary to Ritchie’s (2001) descriptive study which discovered that friends were seen as being supportive, by being available to listen and help the AYA continue with school and social activities as much as possible, although they could not really understand the experience of living with cancer (Ritchie, 2001). This discrepancy could be related to the time of Tebbi’s study with young people living in the 21st century having a greater awareness of cancer and are less apprehensive about supporting their friends with cancer.

Corey et al’s (2008) North American cross sectional study of 127 AYAs with cancer and (n) 72 AYAs recently diagnosed with cancer, sought to describe the relationships of friends, family and health care provider, and social support to pain, fatigue, depressed mood and insomnia. The study demonstrated that perceived social support from family friends and health care providers was an important predictor of mental health and for alleviating the symptom of distress. Lynam’s (1995) Canadian qualitative study of 12, 19-30 year olds with a cancer diagnosis of lymphoma or sarcoma, examined the nature of family work. In particular, the study focused on the nature of support that young people received from and offered to their families. From this study the authors concluded that families play an integral role in offering support to young adults with cancer. The young people in this study spoke of how the cancer had changed their expectations of those around them and how the family provided support to one another. This supportive family involved establishing caring partnerships, acknowledging the possibility of death, putting the illness in its place, looking towards the future and recognising the role of others in supporting the young adult. Of most importance in this study was the family’s ability to be there for the young person who has cancer.

Ritchie (2001) concluded that, because of the degree of social support from families, it was important to meet family’s needs and value their presence and participation during treatment. She also commented that opportunities should be provided for adolescents to have contact with their peers With respect to the health providers, the provision of a primary nurse and physician were seen as an important source of social support for AYAs being able to discuss their condition (Kyngas, et al., 2001). Although, in Ritchie’s (2001) study only one participant identified a health care worker (physician) as being a source of emotional support.

In addition to the support from family, peers and health care professionals AYAs with cancer saw the support from other AYAs, who have had a similar experience, as a need
(Kyngas, et al., 2001; Patterson, et al., 2008a). In Zebrak et al’s (2006) North American delphi survey (which will be discussed in more detail in the Health Care Provision section of this chapter), patients ranked support from other AYAs with cancer as more important than support from family and friends. Cassano and Nagel (2008) conducted a qualitative descriptive study, of 11 adolescents aged 14-20 with cancer in Canada, to explore the adolescents’ perception of a peer support group. The participants found the experience inspiring and welcomed the opportunity to talk to others who know what the experience is of having cancer. However, they also found that dealing with the death of a group member was a challenge that needed to be confronted. The authors concluded that talking to someone who knows, compared to healthy peers, provided support from adolescents who understood.

Zebrack, Chelsey and Kaplan (2010, p. 134) noted that this social support was extremely important for the cancer journey, “Survivors said that positive support often relieved anxiety and isolation, helped put life in perspective, offered hope and inspiration, enhanced ability to make decisions about treatment, alleviated pain and suffering, and improved quality of life”.

**Health Care Provision**

Zebrack Bleyer, Albritton, Medearis and Tang (2006) North American study conducted a Delphi survey with 40 oncology health care professionals and 37 young adults diagnosed with cancer between the age of 15-39 years, to identify important health and supportive care needs for AYA patients and survivors. The study identified the following health care needs for those in treatment: adequate health insurance; a multidisciplinary approach to the delivery of oncology care; and treatment decisions that take into account the risk of successful achievement of developmental tasks with clinical trials and protocols designed specifically for AYAs.

In a review of the requirements for health care provision for adolescents with a chronic condition, Michaud, Suris and Viner (2004) concluded life style issues require unique communication and management strategies from health care providers (Michaud, Suris, & Viner, 2004). Herbertson and Hancock (2005) examined the psychosocial effects of Hodgkin lymphoma in adolescents, as part of their scholarly UK article on Hodgkin lymphoma in adolescents. The authors argue for AYAs to receive adequate psychosocial support during diagnosis and treatment. This support should be
individualised for each AYA’s specific needs. Yeo & Sawyer (2009) in an Australian article which acknowledged the need to understand the emotional and social outcomes of AYAs with cancer, promoted the HEADs framework. HEADs is the mnemonic for “Home, Education and Employment, Eating and Exercise, Activities and Peers, Drugs, Sexuality, Suicide and Depression and Safety” (Yeo & Sawyer, 2009, p. 2) for psychosocial assessment. The authors suggest that a psychosocial assessment of AYAs provides a means of understanding how cancer affects these developmental stages, helps to identify at risk behaviours, helps guide counselling and anticipatory guidance, and helps effect a long term management plan.

Given the importance of health care provision in understanding the complex needs of AYAs, it is important that the health system addresses the needs of this particular group of people. Two main themes emerged in the area of health provision - communication and quality of care.

**Communication**

The literature on coping strategies demonstrated that being provided with information resulted in a sense of control for the AYA. The need for age appropriate, honest information delivered in an individualised and caring way by health professionals, was a theme in many of the articles in this review (Bradlyn, Kato, Beale, & Cole, 2004; Epstein, et al., 2004; Ishibashi, 2001; Kyngas, et al., 2001; Miedema, et al., 2007; Palmer, et al., 2007; Patterson, et al., 2008a; Suzuki & Beale, 2006; Whyte & Smith, 1997; Zebrack, 2008; Zebrack, et al., 2006; Zebrack, et al., 2010; Zebrack & Walsh-Burke, 2004; Thomas, et al., 2006). This ability to provide appropriate information, and to whom the information is provided, is sometimes difficult because of the developmental stage of the AYA (Grinyer, 2002a, 2004b, 2007a; Grinyer & Thomas, 2001) and the type of health system in which care takes place. Patterson, Millar & Desille’s (2008) Australian Report found that paediatric nurses and paediatricians have a limited understanding of how to communicate with this age group and their parents. Further to this, AYAs in the adult system may receive information in ways that are not developmentally appropriate.

Thomas et al’s (2006) overview of AYAs in the health system confirms that health care professionals, in either system of care, are negotiating primarily with mature adults. AYAs complained that neither their confidentiality nor autonomy was respected. This
provision of information in the adult system can create problems for both the AYA and the family. Grinyer & Thomas (2001) and (Grinyer, 2002a) found the ability for the AYA to make independent decisions compounded the parents’ anxiety with respect to cancer and it’s treatment. The authors identified that parents may be excluded from medical information and decisions, thus creating conflict for the parents. Due to their better understanding of the system parents wished to give advice, but at the same time did not want to interfere, due to the AYA’s need for independence. In these two studies (Grinyer, 2002a; Grinyer & Thomas, 2001) some AYAs were given the diagnosis of cancer without family support.

This is despite the fact that Patterson, Millar and Dessille (2008) reported that AYAs ranked having parents present for discussion as a need. In addition, health care professionals who listened and had a sense of humour, and the AYA having more time to make decisions, was also considered as a need. In this Report, the AYAs requested complete and honest information about the prognosis, post treatment, treatment methods, fertility prospects, longterm effects, side effects and what to expect in hospital.

This was confirmed in an earlier Australian study by Dunsmore and Quine (1995). These researchers utilised a descriptive exploratory study to identify the support and information needs of 51 Australian young people with cancer (27 males and 24 females aged 15-24). In this study the young people wished to be informed and involved in decisions making and this included being informed about bad news such as a poor prognosis. The young people preferred this information to come from the treating physician. The young people identified the following as desirable to facilitate communication: listening, concern, professional expertise and honesty. An impersonal manner, technical jargon, haste, and the generation gap were seen to hinder communication.

This requirement for honest information is confirmed in Zebrack et al (2006) delphi survey which also suggested the information should be targeted to the developmental stage of the AYA. Accessing information about their cancer and its treatment increased their self confidence and enhanced positive thinking and belief in treatment (Kyngäs et al 2001).
Bradlyn, Kato, Beale and Cole (2004) in North America conducted a postal survey of paediatric cancer professionals to update and extend a previous survey of oncology professionals’ views about the information needs of adolescent patients with cancer. There were 556 valid returns that found that professionals generally rated medical items as more important to communicate to the adolescents than psychological items. The professionals ranked information about treatment as more important during treatment than at diagnosis. Respondents rated themselves as effective communicators, which was found to be associated with years of experience. This is in contrast to Zebrack, Chelser and Kaplan (2010) North American qualitative study using focus groups. These researchers sought to identify aspects of behaviour that may promote or inhibit healthy psychosocial adjustment for AYAs with cancer. Seventeen young adult survivors aged 18-35, diagnosed with cancer after the age of 18, were recruited to the study. The AYAs found the manner in which the information was given was seen as inadequate and delivered in a cold, aloof and patronizing manner. The research studies discussed demonstrate that AYAs and their families require accurate and honest information about the cancer and the cancer’s effects; how this information is communicated and to whom it is communicated is also of importance.

The use of the internet, to deliver age appropriate information to AYAs with cancer, was seen as a need in Zebrack’s (2008) North American quantitative online survey of 217 young adults aged 18-40 years diagnosed with cancer between the ages of 15-35. The purpose of the survey was to examine supportive care needs and preferences among young adult cancer patients. Decker, Phillips and Haase’s (2004) quantitative and qualitative North American study, with 74 newly diagnosed aged 11-19 patients and then 39 one to three years from diagnosis aged 11-21, described how adolescents with cancer rate the importance of specific cancer information using the Information Preference of Adolescent Scale. The study found that adolescents rated all items on the scale as important which reinforces the adolescents’ need for information. However, this study identified that these adolescents felt only partly informed, or not informed at all, while in hospital.

This is confirmed in Clemente’s (2007) ethnographic study to observe the degree of information disclosure to children and adolescents with cancer and what the child, adolescent and their families wanted to be disclosed, in a hospital in Barcelona, Spain. Clemente studied 17 adolescent cancer patients, their families and clinicians and found
that clinicians used certain strategies to partially disclose or evade direct answers to adolescents’ questions. This study demonstrated that evading direct answers limited the adolescents’ involvement in their treatment and did not diminish adolescents’ uncertainty and anxiety. The author concluded “that if clinicians were to integrate adolescents’ individual information needs into their communication practices they would be able to better assess what information to disclose as well as how and when to disclose it” (Clemente, 2007, p. 19).

This is further reinforced by Britto’s (2004), North American study. The author developed a health care questionnaire in which 155 adolescents, out of a possible 251 with a chronic condition, rated items considered important for health care quality and preferences for communication. The adolescents ranked physician honesty as important in the management of their condition, with lack of disclosure and saying one thing and doing another being considered examples of dishonesty. Adolescents also wanted to participate in their own care and have their viewpoints taken seriously.

**QUALITY OF CARE**

In Britto’s (2004) study interpersonal care was ranked as the most important in the quality of care. A strong emphasis was also placed on health care professionals having an understanding of the technical aspects of caring for the adolescents’ condition. Attention to pain, that included procedures and surgery, was also rated highly. The authors recommended that physicians’ communication skills with adolescents be improved, that physicians avoid the appearance of dishonesty, pay attention to pain and provide time and privacy for the adolescents’ concerns to be heard. This emphasis on care was also evident in Patterson, Millar, and Desille’s (2008) Australian report into the needs of young people with cancer, in which AYAs rated the domain of the structure of care highly, with leisure space and activities, privacy and access to better food being the most prominent unmet needs.

Mitchell, Clarke and Sloper (2006) through a postal survey of 506 families, of which 303 responded, provided an overview of the care and psychosocial support for children, young adults and their families who attended seven UK paediatric treatment centres. They identified the following key areas of satisfaction: leisure and play, support from staff, medical information and preparation for treatment, involvement and independence opportunities, and support for family and peers. However, unmet needs were also
identified in multiple areas. The authors found practical support, lack of and charges for parking spaces, and hospital catering as problems. The provision of age appropriate facilities for young people continued to be a problem. There was a lack of information in a variety of formats and targeted to specific groups, a lack of counselling support for the young person and for other members of the family such as siblings and grandparents. Also, the provision of clear and coordinated transition procedures was required for patients returning home, going back to school or entering into adulthood. The authors concluded that there is a need to develop flexible and equitable packages of support for children, young people and their families.

Palmer, Mitchell, Thompson and Sexton’s (2007) grounded theory study aimed to explore the experience of adolescent cancer patients in Victoria, Australia and to identify areas of unmet physical, psychological and social need. The information was collected through a focus group with six young people who had been diagnosed with cancer. The participants identified a number of concerns related to three main categories: information provision; treatment processes and; survivorship. The participants commented on how much and to whom the information was given. All participants wished to be involved in the decision making processes and to be given comprehensive information about their diagnosis and treatment.

In particular they were concerned about future fertility. These future fertility concerns were raised by the young person or the parent and not raised by the medical staff. All the participants were unhappy with the treatment process, as many found the waiting more stressful than the appointment or treatment, as they became more fearful and isolated. They believed the hospital staff were aware of their needs but the hospital processes could not accommodate their needs. The young people treated as inpatients were unhappy with the physical facilities provided by the hospital and found being in a ward with either older or younger patients distressing. Those who had the opportunity to be treated with other young people found it supportive. All believed the hospital stay could be improved with better food and access to an outdoor area.

There was little counselling support offered to the young people with only one receiving formal psychological support and practical psychosocial support varied according to the institution. The cancer journey resulted in some losing friends and the young people would have liked their school peers to be informed about the cancer and the illness. The attitude of staff made a particular difference to the cancer experience, with the nursing
staff playing a major role. Penson et al (2002) believe the positive attitude of health care professionals is at times challenging. The young person may fluctuate between autonomous decisions maker and an older child during the cancer journey. The adult unit staff may find it difficult for the parent to be involved with care, when the young person regresses due to the demands of a life threatening illness.

FAMILY ISSUES

The family is identified as a major form of social support for AYAs. Neville (2005) believes that the family should be viewed as the centre of care in order to provide comprehensive and sensitive care. The diagnosis of cancer in a young person has a ripple effect on the family and family functioning (Neville, 2005). This is affirmed in Woodgate’s (2006b) interpretive analysis of the stories of 39 children diagnosed with cancer (aged 4.5-18 years, 10 being the mean age) and their families (parents and siblings). The illness narratives developed for the children and their families in this study developed an understanding of childhood cancer from the child and their family’s perspectives. The core narrative of the families was that “life is never the same,” thus demonstrating this ripple effect on the children and their families. Embedded within this core narrative were three other narratives: losses, shared and unique; moving forward, moving on; and it is never over with … always a waiting game.

Woodgate (2006b) determined that the diagnosis of cancer forever changed the family’s life course - this is described by Clarke-Steffen (1993) as a fracturing of reality in the lives of children and their families (as cited in Woodgate 2006b). This study suggests that in order to provide holistic care to families who have a young member with cancer, we are required to have a better understanding of the AYA cancer journey and the impact this has on the AYA’s family. This literature review organised the literature covering family issues associated with the AYAs cancer journey, under the following headings: family, parental and sibling’s experience of the AYA cancer journey.

Life Stage Issues

Rolland’s (1987a) seminal scholarly article describes a conceptual framework of the system created at the interface of chronic illness with the family and individual life cycle - the family system illness model (FSI). This model was seen as still having application to families who are living with a chronic illness in the 21st century. The FSI model provides a map to address the challenges and uncertainties that can be
overwhelming for families living with a chronic illness (Rolland, 1984, 1987a, 1987b). The onset of an illness results in a centrifugal pull on the family system (Rolland, 1987a) with an emphasis on internal family life. This centrifugal pull has repercussions for the AYA and their family as each family’s extra familial autonomy and individuation are at risk, compromising this transitional phase of individual and family development (Rolland, 1984, 1987a, 1987b; Veach, et al., 2002).

Rolland (2005) further developed the FSI model, to describe an integrative model for cancer and the family. Further emphasis was placed on the developmental framework that includes illness development, individual development and family development. Psychosocial developmental challenges were identified which required strength, attitudes or changes for adaptation. Finally, how the families belief system influenced the adaption to the cancer diagnosis, treatment and death were identified. Whilst the family systems illness model provides a generic model for understanding the effect of cancer on the family at particular developmental stages, the model does not provide an in-depth understanding of specific issues for AYAs and their families. The following literature highlights some of the specific issues that impact on the family system model described by Rolland (1987a, 2005).

**Family Functioning**

Bjork, Wiebe, and Hallstrom’s (2005) Swedish phenomenological study interviewed 17 families to elucidate the family’s lived experience when a child in the family was diagnosed with cancer. They described the experience as “a broken world” with an immediate experience of “striving to survive”. The broken life world was experienced as losing their foothold on life and losing their sense of security that resulted in existential thoughts and a different outlook on life as they questioned mortality. The participant’s everyday life was experienced as out of their control, as the family became controlled by the practicalities of the illness. Finally, the family was required to develop a dependence on others and had no choice but to trust the staff.

The second experience was striving to survive - the family acknowledged life had to go on and this was facilitated by hope and a positive focus. The family attempted to reduce the chaos by trying to gain control and reduced their feeling of loneliness by staying close to others. This is an important study that provides an insight into the experience of
a family who has a child with cancer, although the experience may be different for an AYA family given the developmental stage of the AYA and the family.

Evans and Zeltzer’s (2006) literature review identified family cohesion and adaptability as an important psychosocial dimension of cancer in adolescents and young adults. Despite this there was no evidence of an AYA’s family’s cancer journey in seminal literature reviews of 200 clinical papers and research studies written between 1970 and 1991 on the family’s cancer journey (Kristjanson & Ashcroft, 1994). This lack of research of AYAs’ families cancer journey is still evident today with O’Connor’s (2006) report stating there is little evidence of research into the families of AYAs with cancer; although there is ample evidence that the stress associated with cancer affects all family members. O’Connor (2006) identified the following issues for families with a family member diagnosed with cancer: high levels of stress and anxiety, restricted social relationships and practical problems related to disease management and finances.

**Parental Issues**

**EMOTIONAL DISTRESS**

McGrath and Phillips (2008a) published part of a five year Australian longitudinal study which aimed to understand the treatment experience for families coping with childhood lymphoma in 6 children aged 2-13 years. This part of the study, which examined the parents’ perspective of witnessing their child undergo treatment for lymphoma, identified the child’s responses to the toxicity of chemotherapy, the stress associated with invasiveness of accessing a child’s vein and the distress associated with lumbar puncture as the main areas of distress. The study emphasised the need for a full range of supportive services, understanding the emotional impact for the child, clinical strategies to lessen this trauma and contact with other children who have successfully completed treatment. This study also emphasised the distress for parents with a child undergoing treatment for cancer. However, this distress of witnessing treatment may not be as evident with an AYA given their life stage and sense of autonomy.

Further to this Woodgate and Degner’s (2004) Canadian longitudinal qualitative study of 39 families of children with cancer aged 4.5-18 years using grounded theory as a method, identified symptoms as contributing to the children’s and families’ ways of being in the world. There were difficulties associated with taking care of both the child
and the family during periods when symptoms predominate. According to these researchers, this results in the mothers becoming immersed with the child, while the siblings and father formed a new family configuration. Similar to the previous study, this cohort is not representative of the AYA population and the symptom experience may be different for AYA families.

Immersion by the mother in the care of AYAs is confirmed in Grinyer’s (2006a) study in which she conducted narrative study on the health of nine mothers in the UK who had young adults with cancer aged 18-25. In this study the mothers felt isolated, as they provided the intimate physical and emotional care whilst still managing the competing needs of the family and household. Differential emotional engagement between husband and wife further increased this isolation and created a strain on the relationship. The mothers tended to absorb low-grade ill health, with a gap between how the mother feels and how she appears, with many experiencing depression and anxiety. Grinyer (2006a) concluded that the health of the mother maybe seen as invisible when compared to the life threatening illness of the son or daughter.

**Psychological Problems**

O’Connor (2006) identified no difference in psychological distress between patients and carers. The level of psychological distress was influenced by the family’s ability to act openly, express feelings directly to solve problems and to communicate information directly (O’Connor, 2006). Evans and Zeltzer (2006) discovered that maternal adjustment and child temperament were the best predictors of psychological adjustment. In addition, family flexibility and trying to create normalcy were also important.

Allen Newman and Souhami’s (1997) quantitative questionnaire on the emotional impact of the diagnosis of cancer, during adolescence, on patients and their families, researched 43 families; 42 adolescent patients, 34 mothers and, 27 fathers in the UK. They noted that parental anxiety scores were higher than reported norms, with mothers’ anxiety being higher than fathers. Neville (2005) noted subclinical aspects of post traumatic stress disorder (PTSD) existed, such as avoidance of situations associated with the cancer experience.

A North American descriptive quantitative study (Kazak et al., 2004) of 150 adolescent childhood cancer survivors with 146 mothers and 103 fathers, sought to describe concordance rates of PTSD and post traumatic stress symptoms (PTSS) in adolescent
childhood cancer survivors and their mothers and fathers. The study found that PTSS are common in childhood cancer survivors. At least 99% of the sample had at least one family member re-experiencing symptoms of memories, arousal, or avoidance specific to the cancer experience. From this sample nearly 30% of mothers had at some stage met the diagnostic criteria for PTSD and nearly 20% of families had at least one member who fitted this diagnostic criteria. The authors believe this is understandable given the particular events that are associated with cancer treatment for this population (Kazak et al., 2004).

Further to this, in a longitudinal study (Kazak, et al., 2005) of 119 mothers and 52 fathers from 125 families of children currently in treatment for childhood malignancy, investigated the presence of PTSS in parents. The study indicated moderate PTSS for both mothers and fathers (Kazak, et al., 2005). In the families where both parents were in the study, 80% had at least one parent with moderate to severe PTSS. Evan and Zelter (2006) in a literature review to summarise what is known regarding the psychosocial dimensions of cancer in adolescents and young adults, noted that mothers in particular used social withdrawal and avoidant coping to manage the cancer experience. The authors suggest that these PTSD avoidance symptoms to prevent retraumatisation, creates a more rule-bound family function style, therefore minimising the opportunity for the adolescent to develop a sense of identity.

**COMMUNICATION WITH THE AYA**

With regard to the sharing of information, Neville (2005) witnessed displays of guarded communication patterns between the parents and the adolescent with cancer. The AYA with cancer protected their parents from their concerns, as they believed their parents were already overburdened with fear and concern for the AYA. This resulted in a family communication pattern where full disclosure was not always present. In a study by McGrath and Phillips, (2008b), this guarded communication extended to fathers believing that their child did not want to discuss the possibility of death and dying. Alternatively, this was not evident in Grinyer’s (2002a; 2008) studies. In both these studies the parents described talking to their son or daughter about issues that would previously not have been discussed, such as sexuality.
SOCIAL SUPPORT FOR AYA

As already discussed in the previous section in relation to the AYAs’ cancer journey, families were perceived as providing the most social support. Woodgate’s (2000b) review of qualitative research, in order to help advance understanding of childhood cancer from the perspectives of children, found children were sensitive to the sacrifices the family members made in the form of sustained presence, constant vigilance, physical presence and diversion. This is confirmed by Neville’s (2005) North American study that looked at the impact of surviving cancer on adolescent development. The seven young adult survivors in this study, six females and one male, described parents, particularly their mothers, as the most supportive during cancer treatment. The participants spoke with great affection towards their mother and appreciated the caring and sacrifices. Many spoke of an intense bond that developed between the mother and adolescent because of the experience (Neville, 2005). Brown and Barbarin (1996) conducted a North American descriptive study of 124 North American parents of children diagnosed with cancer. They aimed to investigate the parents’ perception of their role in the illness situation. They identified a discrepant parental response to the cancer experience in which the mothers handled the medical aspects of parenting and fathers were more involved with the financial aspects of care. The authors concluded that these discrepancies tend to suggest that the family adaption to childhood cancer may require a traditional gender division of labour, to accommodate the cancer diagnosis. Neville (2005, p.174) stated “Fathers … use increased denial and avoidance, engage in more instrumental tasks, express less emotion than mothers and utilize less social support”.

Two other studies, (McGrath & Phillips 2008b and McGrath & Huff 2003) indicated contrary findings. McGrath and Phillips (2008b), as part of an Australian phenomenological five year longitudinal study of children aged two to 13 years, considered the psychosocial issues associated with the treatment of childhood lymphomas and interviewed six families in which three fathers participated. As another part of this longitudinal study McGrath and Huff (2003) interviewed 13 families, of children aged 17 months to eight years, whose child had acute lymphoblastic leukaemia (ALL) in which six of the fathers participated. Both these studies sought to examine the experience of fathers whose child had these cancers. In each of these studies the authors found the father had a strong involvement and commitment to care. Where possible they
played a role during treatment by involvement with the child patient or well sibling, or through support to the mother. Fathers’ work commitments were found to be an obstacle in providing the care they desired (McGrath & Huff, 2003; McGrath & Phillips, 2008a). These two studies suggested a gender division of labour within the context of the AYAs’ cancer journey with the father engaged as the breadwinner and the mother providing the physical and emotional support.

All these studies emphasised the family involvement with children or young adolescents. There is little evidence of how much or what sort of family support involvement an AYA with cancer requires or wants.

**Health Care Provision**

The psychological distress experienced by parents, as discussed previously, is compounded by the fact that many families required relocation to a specialist metropolitan hospital, particularly in the paediatric system. McGrath and Rogers (2003) in the Australian longitudinal phenomenological study on psychosocial issues associated with paediatric ALL, interviewed 12 families of patients aged nine months to 10 years with ALL. The authors found that relocation was highly stressful for families, in that it disrupts their sense of normalcy and challenges the family’s ability to cope. Whilst this study is confined to families of young children, issues associated with relocation for AYA families may or may not be similar.

In summary Sawyer and Aroni (2005), in their article on self-management in adolescents with a chronic illness, stress the need for progress in developmental appropriate health care which balances the perspectives of young people and their parents. Michaud et al (2004), in a review of health care provisions for adolescents with a chronic condition, suggested that the health care team should understand parents’ responses to the situation and to view their understanding of the AYA as a resource. The authors further emphasised that parents and the AYAs require information about the cancer treatment, thus emphasising the importance of considering family in the holistic management of AYAs with cancer.
Sibling Issues

When considering the impact of the diagnosis of cancer in an AYA’s family system the effect on the sibling should not be forgotten. Research has indicated that siblings can provide support to the AYA during a critical stage of the illness (Spinetta, 1999; Riches & Dawson, 2000). However, it is important to keep in mind that siblings may also require psychological support (Michaud, et al., 2004). McGrath (2008, p. 142) states that siblings “are a vulnerable group who require immediate attention”. The effect of the diagnosis on the siblings can create additional stress on family functioning, as siblings in this position can feel isolated, invisible and left out (McGrath, 2008; Riches & Dawson, 2000).

Psychological Problems

Wilkins and Woodgate (2005) reviewed the historical literature for siblings of paediatric patients with cancer and found that the sibling’s life was changed, accompanied by intense feelings and unmet needs. Siblings can experience the following: jealousy and guilt, anxiety and a sense of responsibility, school problems, feelings of rejection and poor relationships with their parents. Wilkins and Woodgate (2005) concluded that siblings experienced intense feelings of sadness, loneliness and rejection with a disintegration of family dynamics and roles, with some studies pointing to evidence of post traumatic stress.

Spinetta, Jankovic and Eden’s (1999) guidelines for the assistance to siblings of children with cancer suggest siblings may experience the following: problems at school, changes in family routines, loss of family cohesion and expectations as they take on extra household responsibilities. Siblings are often exposed to the physical and emotional suffering of their brother or sister, with a sense of helplessness and hopelessness, and often adopt a caretaking role. In addition to this they are distanced from the support of their parents, with shifts in family role responsibilities. Associated with this is intense distress in parents and long parental absences that may interfere with the successful adaption to this major life stress (Alderfer, Labay, & Kazak, 2003).

In McGrath’s (2008) Australian study she interviewed 12 mothers and 4 fathers in order to understand the sibling experience (aged 0-20 years). Parental insights revealed
siblings felt left out and missed out on normal family existence. For teenage siblings the ties to the outside world were disrupted, due to the unpredictability of the cancer experience, and this resulted in missed employment opportunities and a cancellation of part-time university courses.

Alderfer, Labay and Kazak’s (2003) North American quantitative study investigated whether the stressors, which have been identified in this literature review, could result in adolescent siblings of childhood cancer survivors experiencing post traumatic stress. In this study 78 adolescent siblings, with a mean age 14.2 years, completed a self-report questionnaire that included measures of anxiety, PTSD and perceptions of the cancer experience. The authors found that nearly half the siblings had mild post traumatic stress reactions and almost a third had moderate to severe reactions. Intrusion and avoidance were the main symptoms; over a quarter thought their brother or sister would die during treatment; and over a half reported the treatment as scary and hard. A few siblings believed their sibling with cancer could still die.

Houtzager, Grootenhuis, Canon and Last (2004) conducted a longitudinal follow up study in the Netherlands of 103 siblings 83 in a prospective study and 46 in a retrospective study, to determine the siblings’ psychosocial adaptation to the diagnosis of cancer of a brother or sister. The study found two years after the diagnosis nearly one third of the siblings (aged 11-18 years) reported internalising emotional problems such as depression, anxiety or social withdrawal.

Patterson, Millar and Vissar’s (2008b) Australian research into the needs of young people who have a sibling with cancer, revealed a relationship between unmet need and poorer psychological functioning in the 12-17 year olds. Further, there was a relationship between depression and the unmet need of peer support (friends), access to support services and instrumental support domains in the 18-24 year olds; there was also a relationship between stress and peer support group friends. This research is discussed in more detail when discussing the social support for this group of people.
**SOCIAL SUPPORT**

Patterson, Millar and Vissar’s (2008b) Australian research developed an instrument with ten conceptual domains of needs. Seventy one siblings aged 11-23 years were surveyed to identify unmet needs. This study ranked the most unmet needs from ten conceptual domains in the following order: peer support, acknowledgement and attention to self, access to support services, sibling relationship and support, expressing and coping with feelings, involvement in the cancer experience, information respite, recreation, peer support with peers sharing a similar experience, and instrumental support. It was assumed that peer support with peers sharing similar experience was ranked low as an unmet need, due to the participants all being members of CanTeen.

**ANTICIPATION STAGE**

According to Armstrong-Coster (2004) the Anticipation stage is associated with remission and fear of re-occurrence. This literature review could find no literature associated specifically with the Anticipation stage of the AYAs cancer journey. The literature reviewed in the Exploration stage of the AYA’s journey alludes to this stage of the journey within the psychosocial issue associated with uncertainty about the future (Carlsson, et al., 2008; Decker, et al., 2007; Decker, et al., 2004; Neville, 2005; Palmer, et al., 2007; Patterson, et al., 2008a; Woodgate, 2008). Most of the studies were retrospective to the cancer experience during the Exploration stage. Concerns of normality and identity recognised in the Exploration stage of the cancer journey have been identified by Armstrong-Coster (2004) in the Anticipatory stage of the cancer journey. She describes this stage as a period of trying to maintain a normal life whilst living up to the expectations of a hero’s role. This was at a time when the person’s physical and social identity had undergone a change and they worked towards re-establishing their previous social identity (Armstrong-Coster, 2004).

**Summary: Departure, Exploration and Anticipation Stage**

The following issues have been identified within the literature on AYAs’ Departure Exploration and Anticipation stages of the cancer journey: life stage issues; including delay in diagnosis, identify transformation with repercussion for identity formation, a desire to maintain normality, negative body image and sexuality and infertility.
concerns. Psychosocial concerns include: psychological problems, suffering, uncertainty about the future, coping skills and social support.

The literature highlighted the life stage and psychosocial needs of AYAs with cancer and discussed how many of these issues were not considered in the present system of care. This was evidenced in the literature related to health care provision that demonstrated that there was a lack of understanding of the issues within the present provision of health care. However, the quality of care of the health system and an understanding of the needs of AYAs both psychologically and physically was considered important for AYAs. The literature that informed this understanding of the AYAs’ cancer journey was limited to this discrete group, with most of the issues being identified from studies of adolescents in the paediatric system with the adolescent at times being in a cohort with children. On the other hand some studies included the AYA with older young adults. Therefore, the issues associated with AYA and cancer need to be researched as a distinct cohort.

The literature related to family issues revealed that the diagnosis of cancer puts a strain on the family system. The emotional distress associated with providing support and witnessing the distress of the AYA during treatment, had a detrimental effect on family members’ health. These effects can result in psychological problems such as post traumatic stress, depression and anxiety.

In order to protect the family members from the emotional distress of the Exploration stage of the cancer journey, the AYA would engage in guarded communication patterns. Added to this was the changed family roles associated with providing care to the AYA. This was more evident if the family was required to relocate to support the AYA.

Once again the majority of the studies were conducted in the paediatric system and many were specific to families of younger children with others including younger adolescents in a cohort of younger children and their families. This suggests that further research is required which addresses the specific concerns of family members who are being cared for in both systems of care.

Given the diversity of issues associated with the Departure, Exploration and Anticipation stages of the AYA and the family’s cancer journey, the following model
provides a summary of the issues which were made known in those sections of the literature review (see Figure 2.1). Many of the issues identified in these stages are also relevant to the Destination stage. Although, for the purpose of this review, the literature for the Destination stage will focus on end of life decision making, place of death and the dying trajectory.

Figure 2.1  Issues associated with the AYA cancer journey
**DESTINATION STAGE**

**Death and Dying**

Armstrong-Coster’s (2004) study was based on the experience of adults dying of cancer and, as has been established in the previous section, AYAs with cancer have unique issues and needs as a result of their life stage. The issues associated with the Departure, Exploration and Anticipatory stages of the cancer journey are also present in the Destination stage of the cancer journey. Added to this are the specific issues associated with End of Life (EOL) decision making, place of death, and the dying trajectory.

Given the limited research on AYAs and their families with cancer, there are even fewer research articles that follow the cancer journey through to dying and death. Table 2.3 provides a summary of the literature reviewed for the Destination stage.

**Table 2.3 Literature Associated with the Destination Stage**

<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Study</th>
<th>Areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>Bell, Skiles, Pradham &amp; Champion</td>
<td>Reviewed (n) 103 charts of adolescents who have died of cancer</td>
<td>Place of death EOL Dying trajectory</td>
</tr>
<tr>
<td>2010</td>
<td>Zelcer, Cataudella, Cairney &amp; Bannister</td>
<td>Focus group of parents whose child had died from a brain tumour</td>
<td>Place of death Dying trajectory</td>
</tr>
<tr>
<td>2009</td>
<td>George &amp; Craig</td>
<td>Scholarly article related to issues of palliative care for adolescents</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2009</td>
<td>De Jong &amp; Clarke</td>
<td>Narrative study on what Constitutes a good death</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2008</td>
<td>Wiener, Ballard, Brennan, Battles, Martinez, &amp; Pao</td>
<td>Explored through questionnaire and interviews AYAs EOL concerns by presenting adult aged care directives to AYAs and asking for comment</td>
<td>EOL Dying trajectory</td>
</tr>
<tr>
<td>2008</td>
<td>Bissett, Hutton &amp; Kelly</td>
<td>Scholarly article examined end of life care for AYAs</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2008</td>
<td>Monterosso &amp; Kristjanson's</td>
<td>Semi structured interviews to determine parents experience of palliative care after their child has died of cancer</td>
<td>Place of death Dying trajectory</td>
</tr>
<tr>
<td>Year</td>
<td>Author</td>
<td>Study</td>
<td>Areas</td>
</tr>
<tr>
<td>-------</td>
<td>---------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>2006</td>
<td>Surkan. Dickman, Steindeck, Onelov &amp; Kreicbergs</td>
<td>Postal survey which discovered factors which influenced place of death for parents whose child had died of cancer</td>
<td>Place of death EOL</td>
</tr>
<tr>
<td>2006</td>
<td>Anghelescu, Oakes &amp; Hinds</td>
<td>Scholarly article on issues related to end of life care for paediatric patients</td>
<td>EOL Dying trajectory</td>
</tr>
<tr>
<td>2005b</td>
<td>Hinds, Drew., Oaks, Fouladi, Spunt, Church, et al</td>
<td>Qualitative study to identify factors which influence end of life decisions in children and adolescents with advanced cancer</td>
<td>EOL</td>
</tr>
<tr>
<td>2005a</td>
<td>Hinds, Oaks, Hicks &amp; Anghelescu</td>
<td>Literature review to describe the complexities of end of life care of children and adolescents dying of cancer</td>
<td>EOL Dying trajectory</td>
</tr>
<tr>
<td>2005</td>
<td>Hain</td>
<td>Article related to unique needs of adolescents whilst dying</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2005</td>
<td>Freyer</td>
<td>Article describes the developmental, ethical and legal issues associated with caring for the dying adolescent</td>
<td>EOL Dying trajectory</td>
</tr>
<tr>
<td>2005</td>
<td>Beale, Baile, &amp; Aaron</td>
<td>Case study on communication with children dying of cancer</td>
<td>EOL</td>
</tr>
<tr>
<td>2005</td>
<td>Hannan &amp; Gibson</td>
<td>Phenomenological study to explore decision made by parents as to place of death</td>
<td>Place of death</td>
</tr>
<tr>
<td>2004</td>
<td>Lyon, Mc Cabe, Kantilal &amp; D’angelo</td>
<td>Exploratory study of adolescents with chronic illness to determine what they want with regard to end of life decision making</td>
<td>EOL</td>
</tr>
<tr>
<td>2004</td>
<td>Hurwitz, Duncan &amp; Wolfe</td>
<td>Through a case study examine issues of caring for a child with cancer at the end of life</td>
<td>EOL Dying trajectory</td>
</tr>
<tr>
<td>2004</td>
<td>Clover, Browne, McErlain &amp; Vandeberg</td>
<td>Grounded theory study to explore adult patients understanding of EOL discussions with nurse</td>
<td>EOL</td>
</tr>
<tr>
<td>2004</td>
<td>Grinyer &amp; Thomas</td>
<td>Narrative correspondence method to examine the experience of place of death for AYAs dying of cancer</td>
<td>Place of death</td>
</tr>
<tr>
<td>2004</td>
<td>Hudson</td>
<td>Interviews to explore challenges associated with caring for advanced cancer patients at home</td>
<td>Place of death</td>
</tr>
<tr>
<td>2004</td>
<td>Coyle</td>
<td>Commentary of Hudson’s 2004 study</td>
<td>Place of death</td>
</tr>
<tr>
<td>2004</td>
<td>Perreault, Fothergill-Bourbonnais &amp; Fiset</td>
<td>Phenomenological study on the experience of family members caring for a dying loved one at home</td>
<td>Place of death Dying trajectory</td>
</tr>
<tr>
<td>Year</td>
<td>Author</td>
<td>Study</td>
<td>Areas</td>
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<tr>
<td>-------</td>
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</tr>
<tr>
<td>2004</td>
<td>Harris</td>
<td>Article on palliative care in children and adolescent</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2004</td>
<td>Hind, Pritchard &amp; Harper</td>
<td>Article on research priorities for paediatric oncology</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2003</td>
<td>George &amp; Hutton</td>
<td>Scholarly article related to issues of palliative care for adolescents</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2003</td>
<td>Drake, Frost &amp; Collins</td>
<td>Study examined symptoms prevalence, characteristic and distress of children dying in hospital through medical records and interviews with nurses</td>
<td>Place of death, Dying trajectory</td>
</tr>
<tr>
<td>2002b</td>
<td>McGrath</td>
<td>Qualitative research exploring the experiences of carers of patients dying in the hospital and a hospice</td>
<td>Place of death, Dying trajectory</td>
</tr>
<tr>
<td>2001a</td>
<td>Taylor, Glass, McFarlane &amp; Stirling</td>
<td>Qualitative descriptive study to examine congruency between patients, patients’ families and palliative care nurses</td>
<td>Dying trajectory</td>
</tr>
<tr>
<td>2001b</td>
<td>Penson</td>
<td>Educational case study on negotiating cancer treatment in adolescents</td>
<td>EOL</td>
</tr>
<tr>
<td>2000</td>
<td>Wolfe, Grier, Klar, Levin et al</td>
<td>Descriptive study searched medical records and Interview of 103 parents whose child had died of cancer to determine patterns of care among children who die of cancer</td>
<td>Place of death, EOL, Dying trajectory</td>
</tr>
<tr>
<td>1999</td>
<td>Klopfenstein</td>
<td>Review of adolescents response to cancer and impending death</td>
<td>Place of death, Dying trajectory</td>
</tr>
<tr>
<td>1998</td>
<td>Black</td>
<td>Educational article on the dying child</td>
<td>Place of death, Dying trajectory</td>
</tr>
<tr>
<td>1973</td>
<td>Scholwalter, Ferlot &amp; Mann</td>
<td>Case study of a 16 year old girl with renal failure</td>
<td>EOL</td>
</tr>
</tbody>
</table>
**Destination Stage**

George & Craig (2009) and George & Hutton’s (2003) scholarly articles provide a comprehensive guide to the developmental issues associated with young people with cancer who die, and approaches to care that accommodate this unique group.. This is further reinforced by Hain’s (2005) scholarly article that gives an account of the unique needs of adolescents during the palliative care phase of a life threatening condition. Bisset, Hutton & Kelly’s (2008) article which examined the end of life care for AYAs believe it is important to consider the unique needs of AYAs in palliative care, particularly when intensive support may be required during times of suffering and uncertainty. They refer to the AYAs’ search to create meaning out of dying at a young age. The authors advise that it is important to be cognisant of the AYAs’ developmental phase as this has an impact on how to provide palliative care for this group of people. Finally they say that although “adolescents and young people may have the same physical symptoms as adults, not all are in a position to cope with them or to accept that death is unavoidable” (Bisset, Hutton, & Kelly, 2008, p. 211).

For this literature review a number of studies were deemed suitable for this study, although the majority of the articles focused on younger adolescents and children being cared for in the paediatric system (Beale, Baile, & Aaron, 2005; Bell, Skiles, Pradham, & Champion, 2010; Drake, Frost, & Collins, 2003; Hinds et al., 2005b; Hurwitz, Duncan, & Wolfe, 2004; Monterosso & Kristjanson, 2008; Stillion & Papadatou, 2002; Zelcer, Cataudella, Cairney, & Bannister, 2010). Not surprising the literature identified similar themes to the exploration stage of the cancer journey as being relevant during the destination stage. The themes included psychosocial, physical concerns, existential, self image, sexuality, communication of information, decision making, normalcy, peer relationships uncertainty, and independence and autonomy (Bisset, et al., 2008; Callaghan, 2007; Freyer, 2005; George & Craig, 2009; George & Hutton, 2003; Hain, 2005).

Added to this were fears related to adequate pain control and fear of death itself (Bell, et al., 2010). Furthermore, the psychological stresses associated with the treatment phase for family members were also similar with the added emotional issues of sadness, anger, guilt, exhaustion and insomnia (Hurwitz, et al., 2004). These themes are extended in this section of this literature review to appreciate particular issues related to AYAs and their family’s understanding and management of death and dying. This appreciation is
confounded by the fact that adolescents and their families are rarely exposed to death and dying, few have attended a funereal and even fewer have witnessed a death (Klopfenstein & Young-Salame, 2002). Hurwitz, et al (2004) describe an adolescent’s understanding of death and dying as an enemy to be fought, with dying being seen as a failure or giving up. Beale, Baile and Aaron (2005) say dying adolescents are focused on the future and aware of the time they have left. Connected to this are feelings such as grief, anger, guilt or fear (Freyer, 2005). Denial has also been identified as a universal response for adolescents confronting a terminal illness (Freyer, 2005; Klopfenstein, 1999a).

This literature review discovered specific issues that relate to the palliative phase of the cancer journey. They include end of life decision making, place of death, and the dying trajectory.

**END OF LIFE DECISION MAKING**

Once it has been identified that the cancer is terminal, the AYA and the family is required to decide about the elements of palliative care to be used. These included choices about symptom control, place of care and who provides the care (Freyer, 2005).

Penson et al (2002) in an educational case study on negotiating cancer treatment in adolescents, describes end of life decisions as the hardest part of the cancer journey for parents. Factors that are important include information, assurance that all curative options have been attempted and for parents to have trust in the health care team. These end of life decisions are further compounded by the developmental stage of the AYA, with many adolescents taking a fully active role in making choices for themselves. Lyon, McCabe, Kantilal and D’angelo (2004) conducted a North American exploratory study of 25 adolescents with a chronic illness and 25 adolescents without a chronic illness (aged 13-21 years). They found 96% of chronically ill patients want to share in the decision making if they were very ill, in comparison to 88% of the healthy teens. Eighty percent of the chronically ill and 68% of the healthy teens believed that the doctors would respect their wishes.

Hinds, Oaks, Hicks and Anghelescu (2005a) and Hinds et al (2005b) North American qualitative studies, interviewed 20 children and adolescents aged 10-20 years and
identified the preferences and factors which influence end of life decisions for children and adolescents with advanced cancer. The participant’s end of care decisions included terminal care versus further disease directed therapy, enrolment versus non enrolment into a study for toxicity for a new drug in patients who could not be cured, and the adoption of a Do Not Resuscitate status versus a Resuscitate status. The authors stated that “these patients were able to negotiate a complex decision process during which they considered more than one element at a time and were able to integrate these diverse elements into a decision” (Hinds, et al., 2005b, p. 9150). The study confirmed that this age group was well aware of the consequences of end of life decisions and supports children and adolescents being involved in end of life decisions making. Consensus in the USA is that adolescents 14 years and over are competent to make end of life decisions for themselves. This creates for the AYA a sense of present day autonomy (Freyer, 2005). Freyer (2005), George and Craig (2009) George and Hutton (2003) and Beale et al (2005) all agree that in order for the dying adolescent to understand and make informed decisions, parents and physicians from the commencement of treatment, commit to open honest communication with the young person. This effective and compassionate communication with children and their families is associated with high quality, end of life care and the establishment of realistic goals (Hurwitz, et al., 2004). Further to this, the earlier the child and the family are aware of the terminal nature of the illness there is a better integration of palliative care and an improved quality of life (Hurwitz, et al., 2004).

An extension of the AYA being able to make end of life decisions is the capacity for the adolescent to choose the right to die. This is highlighted by Schlwalter, Ferholt and Mann’s (1973) case study of a 16 year old girl with renal failure, in the adolescent ward at Yale—New Haven Hospital, who refused treatment in order to die. This case study illustrated the developmental, psychological, moral and legal considerations that must be taken into account with regard to this end of life decision. The authors concluded that, in certain instances, the adolescent’s right to die should be honoured.

At present there are no planning guidelines for EOL decisions with adolescents and young adults in the US (Wiener et al., 2008). Weiner et al’s (2008) US study explored, through questionnaire and interview of 20 AYAs living with life limiting illness and identified specific concerns important for adolescents and young adults in planning end of life care. The participants were asked to comment on advanced care directives for
adults to determine what advanced care directive would be suitable for them. The authors concluded adolescents and young adults are open and interested in discussing their EOL care.

This ability to make end of life autonomous choices is compounded by the system of care in which the AYA is cared. They could be subjected to either adult or paediatric palliative care practices (George & Craig, 2009; George & Hutton, 2003). Wolfe, Grier, Klar, Levin et al (2000) during 1997/1998 interviewed 103 parents whose child had died of cancer in Boston between 1990-1997. Additional data was obtained by examining medical records. The study found children treated in the paediatric hospital were more likely to receive aggressive treatment of the cancer, while decisions to withhold aggressive treatment occurred within older age groups; providing some evidence that older adolescents and young adults are more involved in EOL decisions. Wolfe’s et al (2000) study also demonstrated the longer the intervals between the discussion of hospice care and death, the more likely the child was to be calm and peaceful during the last month. These studies suggest that having the opportunity and time to discuss EOL issues results in a more peaceful death.

Clover, Browne, McErlain and Vandeberg’s (2004) Australian grounded theory study interviewed 11 patients in palliative care settings to explore their understanding of EOL discussions with nurses. The authors discovered that involvement in EOL decision making is influenced by the context in which the decision is made, with different decision making approaches being used at different times and in different circumstances (Clover, Browne, McErlain, & Vanderberg, 2004). The authors suggest that health care professionals need to be cognisant with these factors to ensure information passes freely in both directions (Clover, et al., 2004). This study focused on adults in palliative care and the identified issues for adults could have a different emphasis for AYA end of life decision making.

PLACE OF DEATH

Associated with EOL decisions is the decision concerning place of death for the AYA. The AYA’s dying trajectory can occur in the following places: the paediatric or adult hospital, hospice and palliative care at home. The place of death has been demonstrated to influence the dying trajectory for AYAs and their families. Black (1998) in her educational article on the dying child, as part of a British Medical Journal series on
dealing with loss, documented that parents are more anxious, depressed and defensive after death in a hospital than at home. Grinyer & Thomas (2004), Bell, Skiles, Pradham & Champion (2010) and Hinds Prichard & Harper (2004) identified the preference for most people with terminal cancer to die in their own home and this is supported by Foreman, Hunt, Luke & Roder’s (2006) Adelaide (Australia) population survey. In this study 70% of 2652 respondents expressed a desire to die in their own home. Despite this the number of cancer patients who die in their home is relatively small (Bell, et al., 2010; Foreman, et al., 2006; Grinyer & Thomas, 2004; Hinds, et al., 2004) suggesting that preferences fail to be fulfilled during the terminal phase of the cancer journey. In Foreman et al’s (2006) population survey this strong preference to die at home was particularly evident for young people.

The fact that preferences to die at home may not be considered could be a reflection of the curative medical system in which cancer is treated and, as such, carers and patients not being aware of alternative options. Stillion and Papadatou (2002) hypothesised that because of the unacceptability of child and adolescent dying, family and medical personnel often fight longer with aggressive treatment for younger people who are dying, and the opportunity to make end of life decisions about where to die can be lost.

Drake, Frost & Collins (2003) conducted a study in Auckland, New Zealand and Sydney Australia that examined medical records and interviewed nurses to determine the symptom levels and characteristics and distress of 30 children with a mean age 8.9, who were dying in hospital. These researchers discovered high symptom levels, although this was accompanied by low levels of distress; they further found that high levels of comfort were accompanied by higher levels of symptom relief in the intensive care unit (ICU). This symptom relief was accompanied by a high degree of medical intervention.

The 20 out of 30 children who died in the intensive care unit in Drake et al’s (2003, p. 599) study “were invariably ventilated, sedated, receiving analgesics and muscle relaxants; and just under half were comatose at the time of recruitment”. This is verified in Wolfe et al’s (2000) study where half the children who died in hospital died in intensive care and received ventilator support in the last 24 hours of life. The fact that the majority of adolescents die in an acute curative system is affirmed by Bell, Skiles, Pradham and Champ’s (2010) US quantatative study which reviewed the medical records of (n) 103 charts of adolescents, aged 10-21, who had died of cancer. The
authors found that 80% of deaths occurred in hospital as a result of the progression of the cancer. Nearly 12% of the deaths were associated with aggressive life sustaining measures and nearly half of the deaths occurred in ICU. The study demonstrated that 50% of EOL conversations occurred in the last 30 days of life, with adolescents diagnosed with leukaemia/lymphoma having ELO conversations in the last seven days of life, providing little time to prepare for death and engage in EOL decisions. Documentation rarely identified if the adolescent was included in these EOL discussions. The authors concluded that knowing when to transition from curative to palliative care was a challenge in paediatric oncology, with the line becoming more blurred with a diagnosis of leukaemia and lymphoma.

Wolfe et al (2000) suggest one of the reasons for this is that the primary goal of treatment for childhood cancer is cure. The consideration of toxicity, the quality of life and growth and development was seen as secondary. Hinds, Pritchard & Harper (2004) believe that accurate diagnosing of when a child or adolescent is dying would provide families with the time to choose a model of care which best suits them.

A Swedish population-based study supports the preference for children to die at home. In this study 499 parents who had lost a child to a malignancy during 1992 and 1997 were contacted by an anonymous postal survey. This survey found that parental awareness of imminent death resulted in the parent caring for the child at home during the last month (Surkan, Dickman, Steineck, Onelov, & Kreicbergs, 2006). This study provides further support for the notion of timely and honest communication about EOL decisions in order for patients and their carers to be able to make informed choices. This is reinforced in Wolfe et al’s (2000) study that suggests palliation may need to be incorporated with curative treatment where the likelihood of long term survival is low.

This blurred line between curative and palliative, and when to initiate EOL discussions, was reinforced in McGrath’s (2001a, 2002a) qualitative Australian research that analysed the experience of patients dying in a curative system in comparison to hospice/palliative care. McGrath interviewed 9 carers and found their descriptions of the hospital system were negative with a feeling of alienation, depression and powerlessness, and with the invasive technology for some causing post traumatic stress. In contrast, the Hospice group of carers spoke of excellent care support and symptom control. In comparison the hospital carers found they were required to advocate for the patient’s symptom relief. Both groups would have appreciated the opportunity for the
patient to die at home, although there was evidence of a lack of confidence to do this. In this study carers in the curative system were not provided with information about alternative places to care for the patient. McGrath (2002b, p. 45) concluded “patients and their carers are being trapped in a high–tech, curative treatment that does not acknowledge dying and does not appropriately refer to the palliative system”. McGrath based this conclusion on the following: whilst the carers were aware that the patient was dying, the doctors were not open to this fact. The curative system provided a sense of hope, which competed with the existing emotion and of acceptance of the dying. This sense of hope for a cure resulted in the patients stoically undergoing invasive procedures, often resulting in exhaustion and distress. All participants spoke of the patient’s desire to die at home that was associated with dislike of hospitals. When patient did request to die at home it was too late in the dying phase and the patient’s request was denied. All patients in this study died in the hospital setting. McGrath (2002a p. 20) also concluded “that appropriately timed, well informed referral to the palliative system would have made an important contribution to reducing the dissatisfaction, distress and regrets and spiritual pain that was experience by the hospital group”.

This is supported by Monterosso and Kristjanson’s (2008) study that obtained feedback from semi-structured qualitative interviews from 24 parents in five Australian tertiary paediatric oncology units, 10 from Perth, five from Melbourne, five from Brisbane and four from Sydney. The study focused on children who had died of cancer and explored parents experience and understanding of palliative care. They relate that early recognition of a child’s prognosis creates stronger emphasis on lessening suffering and integration of palliative care.

The American Society of Clinical Oncology survey of paediatric oncologists, regarding their attitudes and practices in end of life care, found barriers in integrating palliative care. The study found unrealistic expectations by the family, family denial and conflict, patients’ unrealistic expectations and patient denial. Grinyer & Thomas (2004) used the narrative correspondence method with 13 parents to examine the experience and place of death concerns for an AYA dying of cancer. In this study two thirds of the young people died at home. The authors believe the alienating hospital experience contributed to the young person’s wish to die at home. The parents wrote of how a home death provided the opportunity to be surrounded by family and friends and to provide a sacred
space where the young person had died. Monterrosso and Kristjanson (2008) study noted that parents’ desire to care for the child at home coincided with the need to spend increasing amounts of time with their dying child.

On the other hand the wish to die at home was not always possible, as Zelcer, Cataudella, Cairney and Bannnister (2010) discovered in their focus group interviews with 25 parents of 17 children who had died of a brain tumour. Despite wanting to die at home there were barriers to achieving this outcome, which included an inability to manage the symptoms at home, the financial and practical hardships and whether or not there was adequate support within the community.

Hudson’s, (2004) Australian exploratory study with primary family carers of 47 advanced cancer patients, (mean age 60 and two thirds female), identified similar challenges. Findings revealed the carers’ ill health, lack of skills to manage the symptoms, lack of support from health care professionals, additional stress from other family members, the stress of watching the loved one deteriorate before their eyes, the uncertainty of what next and having no time for self, were obstacles to dying at home. Although, less clearly articulated, 60% of the participants in this study spoke of the positive aspects of a loved one dying at home which included a sense of being a stronger person, the ability to care for the person they love, being together and becoming closer. It should be noted that the age and sex of the family members in this study could have influenced how the carer managed the experience. In addition to this there was no mention of the family carers’ relationship with the advanced cancer patients.

Hannan & Gibson’s (2005) UK interpretive phenomenological analysis of five families whose child had died of cancer explored the decisions made by parents as to place of death. The parents found the decision as to where to care for the child during the dying trajectory was based on the wish to value the time left. The parents did not make a conscious decision to be home; rather the place of care seemed obvious and natural. The care at home provided a sense of normality where family life could continue. The decision was also influenced by the child’s wishes that were associated with previous negative hospital experiences. This ability to care for the child at home was also related to the amount of health care support received, which made the parents feel more in control of the process. The uncertainty of what to expect, and how long the dying trajectory would last, created exhaustion and stress for the family, with many wanting
respite towards the end. The participants also noted a difference in care from those health care professionals with specialist knowledge compared to others. These studies suggest that the capacity to care for an AYA at home is dependent on numerous factors.

Coyle (2004) in her commentary on Hudson’s (2004) study called for more research into this area. The author asked the following questions: what kept the caregivers at home and what caused their distress? - was it the pain of the situation, the reality of death, uncontrolled symptoms, lack of physical help or exhaustion and sleep deprivation?

Perreault, Fothergill-Bourbonnais and Fiset’s (2004) conducted a phenomenological study of 6 primary carers and 4 support persons. The ages of the participants in this study was not mentioned but all were required to be over 18 years. The participants were asked to describe the experience of a family member caring for a dying loved one at home. The decision to care for the loved one at home was initiated at the time of diagnosis. As the illness progressed the caregivers felt a sense of helplessness and isolation, which was associated with the inability to relieve the patient’s pain and discomfort and watching the suffering associated with the progression of the disease. This was compounded by a lack of support from health care professionals and the physical and emotional limitations of the carer to provide the care required for their loved one. These factors were associated with the decision to admit the loved one into palliative care. “Participants stated that this decision to admit reinforced their sense of helplessness” (Perreault, et al., 2004). Although positive aspects were identified, the decision to admit was associated with the ability of palliative care to successfully manage the symptoms of dying, and the carer being able to convert back to their former role. Due to not being aware of the age group of the participants in this study, it is difficult to conclude if this study applies to carers who have a young family member dying at home.

Grinyer and Thomas’s (2004) study of the young people who died in a hospice or hospital, found that if the deaths were handled with sensitivity and respect for the dying person’s individuality and comfort was provided for the parents, the death was less traumatic. This suggests if a home death is not possible, and dying can be handled with compassion and care, that death in a hospice or hospital need not be a negative experience. These findings were confirmed by Klopfenstein (1999) who reviewed adolescents’ psychological response to cancer and attitudes about impending death. She
believes most adolescents will accept hospice care as a place to die as the environment empowers the person to make choices and advocates for their wishes.

**THE DYING TRAJECTORY**

The dying trajectory is associated with the experiences of physical deterioration until the moment of death and this trajectory is not pleasant. Research has found that parents observed that their child endured sustained suffering during the last month of life (Anghelescu, Oakes, & Hinds, 2006; Hinds, et al., 2004; Wolfe, et al., 2000). Harris (2004) in his article on palliative care in children with cancer, indicate that one of the problems associated with managing palliative care in children and adolescents is that death in children and adolescents is a rare event and cancer in children is not common. Added to this is the fact that few paediatric oncologists are trained in palliative care with most learning by trial and error or from a role model (Harris, 2004).

Wolfe et al’s (2000) study, mentioned previously in this section, revealed 80% of the children died of the progression of the cancer and the rest from treatment complications. This study found that most patients received aggressive treatment at the end of life. This was associated with substantial suffering and symptom management was seldom successful. Parents reported that less than 30% had successful pain and dyspnoea management and in only 10% was there appropriate management of nausea, vomiting and constipation. Added to this the parents reported the children had little or no fun, were sad, were not calm and peaceful and were often afraid, reflecting a poor quality of life for these children (Wolfe, et al., 2000). Lack of involvement from the oncologist was associated with more suffering with pain. Despite this, symptoms and suffering are rarely studied in this patient population (Harris, 2004; Hinds, et al., 2005a).

Hinds et al (2005a) and Anghelescu, Oaks, Hinds (2006) provide comprehensive literature reviews on how to manage these symptoms and the suffering that accompanies them. Hinds et al (2005a) concluded providing compassionate care to children who are dying and their parents is complex. Anghelescu et al (2006) indicate the process involves deconstructing discrete problems that are reconstructed into a more holistic approach. Consequently all the dimensions associated with palliative care i.e. physical, psychosocial and spiritual, in an attempt to relieve suffering, preserve dignity,
meaning and the value of life until the last moment, need to be considered. Hinds, Pritchard & Harper’s (2004) article on research priorities for paediatric oncology articulated five areas of research in end of life care for paediatric and adolescent cancer patients. These are: 1) symptom management, 2) EOL decision making, 3) the dying trajectory and preferred model of care for the patient and their families, 4) the characteristic of the death and its influence on survivorship and 5) financial considerations. The authors of this article concluded “that preventing or diminishing suffering in a dying child may well have an acute and lasting effect for the bereaved survivor” (p. 178).

This lack of understanding of the dying trajectory is seen in Monterosso and Kristjanson’s (2008) study mentioned previously in this section. The findings affirm that the dying trajectory for parents, whose child died of cancer, is tempered with chronic uncertainty and apprehension in which parents attempt to manage the practicalities of caring for a dying child. Within this context, parents constructed palliative care negatively, with little understanding of palliative care having a wider continuous process. This lack of understanding of palliative care is also found with health care professionals.

Zelcer’s et al’s (2010) qualitative analysis of focus groups involving 25 parents, whose children had died of a brain tumour was conducted in a London Children’s Hospital (England). In the focus groups the parents spoke of ways of coping during the dying trajectory that included maintaining hope. McGrath (2002b) and Monterosso and Kristjanson’s (2008) studies, mentioned previously, support this and found that parents had the ability to hold on to two dichotomous beliefs: the reality of the dying trajectory and the hope of a miracle. This can result in an indirect communication style with health care professionals in which the parents favour communication that maintains hope (Monterosso & Kristjanson, 2008). This has the potential to hinder or augment resilience for the carer and requires a better understanding of the dying process. The resilience and admiration the parents had for the child dying of cancer, particularly for adolescents, provided strength to continue the journey and also assisted carers along the dying trajectory (Zelcer, et al., 2010). Of profound significance for the ability for parents to cope with the dying trajectory, was the health care professionals’ ability to provide compassionate care which was augmented with a continuous relationship defined by honesty, respect and authenticity (Monterosso & Kristjanson, 2008).
parents also wished for a more comprehensive approach to palliative care in order for them to be able to facilitate a good death for their child (Monterosso & Kristjanson, 2008).

De Jong and Clarke’s (2009) narrative study of what constitutes a good and bad death for three persons in each of the following categories - patients (aged 60 to 80 years), primary carers, physicians, unit nurses, and home consultation nurses, - found the following themes: a good death was dying where one wishes; not dying alone; having a sense of a life well lived; having a long life; having the opportunity to say goodbye and prepare for death; and a death free from pain and suffering. A bad death was associated with loss of control and independence. Communication with the health care team was considered important. This importance of communication with the health care team is further emphasised in an Australian qualitative storytelling study by Taylor, Glass, McFarlane & Stirling (2001). The research aimed to examine the degree of congruency between the perceptions of 15 nurses, 5 adult patients and 6 patients’ families respectively. The study explored the nature and effects of palliative care nursing. The patients and the patients’ carers emphasised the personal qualities that a nurse brings to palliative care equal to the nursing activities in which they engage (Taylor, et al., 2001).

A reoccurring theme from the literature was the opportunity to talk about death during the dying trajectory. In Wiener et al (2008) study of AYAs’ concerns in planning end of life care, mentioned previously, only 45% of the participants had spoken to their parents about end of life care. This lost opportunity was seen by the participants in Zelcer et al’s (2010) study that explored the end of life experience of children and their families who died of a brain tumour, as a sense of regret.

Chantelle’s (2004) narrative study conducted 30 interviews, 13 with seriously ill children and young people aged 5-20 years and the remaining interviews with parents and health care professionals working in paediatric care. The stories of these young people provide an understanding of the lived experience of being young and suffering from an advanced or terminal illness. From the stories in this study Chantelle suggested several strategies for communicating with children and young people who are dying, from both an interpersonal and organisational perspective. This study provides strategies that may be useful in opening the dialogue with regard to the AYA’s cancer journey.
Previous literature in this section spoke of the symptoms associated with dying and how these are managed, at times not well. The author could find no research on the actual moment of death, although the need to spend time with and care for the body after death was considered important for the participants in McGrath’s (2002a) study.

**Summary: Destination Stage**

In summary there is limited research on families and AYAs’ death and dying with only two authors Bisset et al (2008) and Hain (2005) providing information specific to this group and their specific psychosocial needs. Bisset et al (2008, p. 211) identified the following needs for AYAs, their parents and siblings from palliative care services: “involvement in decision making, attention to developmental needs, an appropriate setting of care, ambivalence about taking on an adult role, a desire for independent living, the importance of school, college and employment, opportunities to do things that other young people do, symptom relief and emotional support, planning of care to ensure the best end of life care possible” (Bisset, et al., 2008, p. 211). I could find no research that specifically focused on AYAs and the dying trajectory, with the majority of the articles relating to children.

The following model illustrates the issues uncovered in the literature review that applies to the Destination phase for AYAs and their families. The concerns related to the Destination stage of the dying journey include end of life decision making, place of death and the dying trajectory for AYAs and their families. Figure 2.2 illustrates these concerns.
Summary:  Stages of the AYA’s and Family Members’ Cancer Journey

The review of the literature identified issues with the AYA and their family’s cancer journey. Armstrong-Coster’s model of the stages of the cancer journey provided the structure to organise the literature. The following stages Departure, Exploration and Destination provided this structure with the Anticipation stage not evident in the literature. The model in Figure 2.3 illustrates the concerns that have been identified within these three stages for the AYA and the family. This model provides a holistic picture of the AYA’s and family members’ cancer journey.
CONCLUSION

The previous chapter and the article by Hasse & Phillips (2004) and report by O'Connor (2006) in this chapter, have identified that there is little research on the specific issues associated with AYAs with cancer, prompting Michelagnoli, Pritchard & Phillips (2003) to describe this group of people as a ‘lost tribe.’ This chapter sought to identify from the literature knowledge which can further enhance our understanding of the cancer journey for the AYA and their family. This literature was organised using the cancer stages identified by Armstrong-Coster (2004): Departure, Exploration, Anticipation and Destination.

The literature associated with the Destination stage of the cancer journey highlighted similar issues in the studies being carried out in the paediatric system with children and adolescents or studies of dying older adults and their carers.

The review uncovered studies which demonstrated how the cancer journey affects both the AYA patient and the family. In particular, the literature associated with the Departure, Exploration and Anticipation stages of the cancer journey uncovered life stage and psychosocial issues, in addition to issues associated with health care provision as a result of these life stage and psychosocial issues. The literature associated with the
Destination stage of the AYA and their family was limited to studies of children and their parents, or the carers of older people dying of cancer. There was no literature associated specifically with AYAs and their families. This literature identified EOL decision making, the place of death and the dying trajectory as areas that are, at times, not fully addressed in the AYAs’ and their families cancer journey.


There were seven studies that looked at the relationship or correlation between cancer and psychosocial issues associated with cancer (Anghelescu, et al., 2006; Black, 1998; Corey, et al., 2008; Hain, 2005; Hinds, et al., 2005a; Neville, 1998; Whyte & Smith, 1997). Questionnaires and Surveys were a common research method with 15 studies using these methods to further understand the cancer journey (Alderfer, et al., 2003; Allen, 1997; Decker, et al., 2007; Foreman, et al., 2006; Houtzager, et al., 2004; Kazak, et al., 2005; W. Mitchell, et al., 2006; Monterosso & Kristjanson, 2008; Patterson, et al., 2008a; Patterson, et al., 2008b; Surkan, et al., 2006; Wiener, et al., 2008; Zebrack, 2008; Zebrack, et al., 2006; Zebrack & Walsh-Burke, 2004).

To further enhance this understanding 10 semi-structured interviews increased our understanding of the cancer journey for this study (Drake, et al., 2003; Hinds, et al., 2005b; Hudson, 2004; Kyngas, et al., 2001; Larouche & Chin-Peuckert, 2006; Lyon, et al., 2004; Miedema, et al., 2006; Monterosso & Kristjanson, 2008; Tebbi, et al., 1985; Wiener, et al., 2008). Added to this were four ethnographic studies which provided some insight into the culture as to the landscape of the cancer journey (Armstrong-Coster, 2004; Bradlyn, et al., 2004; Britto, et al., 2004; Cassano, et al., 2008; Clemente, 2007; Decker, et al., 2004).
There were four qualitative descriptive studies (Woodgate, 2008 #451; Taylor, Glass, McFarlane, & Stirling, 1997; Woodgate, 2005, 2006a, 2006b). Focus groups provided a group understanding of the common concerns relevant to this study, with 10 studies adopting this method to increase our understanding of the cancer journey (K. Brown & Barbarin, 1996; Dunsmore & Quine, 1995; Lynam, 1995; Neville, 1996; Ritchie, 2001; Taylor, et al., 2001; Wolfe, et al., 2000; Zebrack, et al., 2010; Zebrack & Walsh-Burke, 2004; Zelcer, et al., 2010). Seven other studies, because of the limited research and understanding in this area, used grounded theory as the methodology of choice (Clover, et al., 2004; Costain Schou & Hewison, 1999; Grinyer, 2007a, 2007b; Mathieson & Stam, 1995; Miedema, et al., 2007; Palmer, et al., 2007; Woodgate & Degner, 2004).

There was limited research on the lived experience and the stories associated with the cancer journey. There were 13 studies which used phenomenological methodology (Bjork, et al., 2005; Carlsson, et al., 2008; Hannan & Gibson, 2005; McGrath, 2001a, 2001b, 2002b, 2008; McGrath & Huff, 2003a, 2003b; McGrath & Phillips, 2008a; McGrath & Phillips, 2008b; McGrath & Rogers, 2003; Perreault, et al., 2004), and eight which relied on narrative as the methodology of choice (De Jong & Clarke, 2009; Grinyer, 2002a, 2006a, 2008; Grinyer & Thomas, 2001, 2004; Kameny & Bearison, 1999; Sumni Lee, 2001). The majority of the phenomenological studies, nine in total, had McGrath as the principal author with the most studies being conducted with parents, children and adolescents within the paediatric system of care. Of the narrative studies Grinyer appeared to be the only author to focus primarily on AYAs and their families’ experience of the cancer journey, namely from a life’s stage perspective. This suggests there is limited research on the experience for AYAs and their families as they embark on the cancer journey.

In addition to limited literature on the cancer experience for the AYA patient and their family, of the studies reviewed in this chapter, 10 of the studies were conducted within the paediatric system (Cassano, et al., 2008; Hendricks-Ferguson, 2006; Kazak, et al., 2005; McGrath, 2008; McGrath & Huff, 2003a, Mitchell, et al., 2006; Woodgate, 2005, 2008; Zebrack & Walsh-Burke, 2004) with three studies focusing specifically on children (McGrath & Phillips, 2008a; McGrath & Phillips, 2008b; McGrath & Rogers, 2003). As a result of this, ten of the studies include AYAs and their families in the same cohort as children under 12 and as young as three (Britto, et al., 2004; Epstein, et al., 2004; Houtzager, et al., 2004; Ishibashi, 2001; Kazak, et al., 2005; McGrath & Huff,
Five other studies focused specifically on young adolescents being cared for in the paediatric system and excluded young adults (Carlsson, et al., 2008; Larouche & Chin-Peuckert, 2006; Ritchie, 2001; Woodgate, 2005, 2006a). Further to this, five studies include adolescents and young adults in a cohort of young adults in their early 40s (Miedema, et al., 2006; Miedema, et al., 2007; Zebrack, 2008; Zebrack, et al., 2006; Zebrack, et al., 2010). These five studies, in addition to Tebbi et al (1985) and Neville’s (2005) studies, focus on survivorship or life after the cancer journey.

In this review I could find only seven studies that fit the definition of AYAs as a cohort defined in this study (Grinyer, 2002a, 2006a, 2007a; Kyngas, et al., 2001; Palmer, et al., 2007; Patterson & Millar, 2008; Patterson, et al., 2008b). From these studies only Grinyer (2002a, 2008) and Grinyer & Thomas (2001) focussed on the AYA cancer experience for the parent and Grinyer (2007a,b) on the cancer experience for the AYA. Grinyer’s focus was mainly on life stage issues associated with this group. Grinyer’s 2006a study also focused on the mother’s health both during the cancer journey and after the death of the son or daughter.

As with the Departure, Exploration and Anticipation stages of the cancer journey the thirteen articles in the Destination stage focused on the younger adolescents and children being cared for in the paediatric system (Beale, et al., 2005; Bell, et al., 2010; Drake, et al., 2003; Hannan & Gibson, 2005; Hinds, et al., 2005b; Hurwitz, et al., 2004; Monterosso & Kristjanson, 2008; Penson & Slevin, 2002; Stillion & Papadatou, 2002; Surkan, et al., 2006; Wolfe, et al., 2000; Zelcer, et al., 2010). The remaining studies focused on issues associated with death and dying for adults (Clover, et al., 2004; Foreman, et al., 2006; Hudson, 2004; McGrath, 2001a, 2002b; Perreault, et al., 2004; Taylor, et al., 2001) or for AYAs with life a threatening illness (Lyon, et al., 2004; Wiener, et al., 2008). The only study specific to AYAs identified in this study was Grinyer and Thomas’s (2004) study on place of death. This literature review could find no studies associated with the cancer journey for AYAs and their families that culminates in death. Although, of the parents interviewed in Grinyer’s (2002a) study, all but seven of the participants’ son or daughter had died. Her study speaks of the emotional impact of caring for a son or daughter with cancer during the treatment and when and after they die.
From this extensive review of the literature it is evident that there is limited research on the experience of the AYA cancer journey. The majority of the studies that address specific AYA issues, focus areas of unmet needs for AYAs. The studies do not articulate the AYA’s or their family’s experience of these unmet needs. Grinyer is the only author who explores these issues for this particular group of people, through the stories that parents and AYAs tell of the experience of the cancer journey. There is no literature on the dying experience for this group of people and only limited research on the experience for families. Added to this, is that this literature review could find no articles which focused on the experience of death and dying for AYAs and their families. This study will increase the understanding of the cancer journey for AYAs and their families and provide further insights on how to care for this unique group of people.

The next chapter examines why the use of narrative inquiry was seen to be the most appropriate methodology to explore the experience of family members as they travel the cancer landscape with the AYA whose final destination is death.
CHAPTER THREE: NARRATIVE AS THE METHODOLOGY

The meaning of stories.

“Storytelling is the most powerful way to put ideas into the world today.”

Robert McKee (http://storyteller.net/articles/160)

INTRODUCTION

The purpose of this chapter is to demonstrate how narrative inquiry is seen as an appropriate methodology for this study. To achieve this, the reasons justifying a theoretical perspective are required to create meaning for the research study. After reviewing the major research paradigms the reader is introduced to why an interpretive qualitative paradigm was believed to be the paradigm most suited for this study. The interpretative methodology of narrative inquiry is introduced and its suitability for the topic of this research study examined. An explanation of narrative inquiry is introduced and relevant contemporary theories that have contributed to my understanding of narrative inquiry are discussed. How this understanding influenced this study is also explored. To support the application of narrative in health sciences, in particular the cancer and death and dying narratives, examples of narrative research in these fields are introduced. Finally, why narrative inquiry was seen to be the most appropriate methodology for the sensitive nature of the research topic, due to my own subjective experience of having my 17 year old son die of cancer, and the experience of the family members who consented to be a part of the study, are summarised.
THE NATURE OF KNOWLEDGE

In order to decide on the methodology, most appropriate for this research study, an understanding of the major paradigms which guide current understanding of research inquiry need to be identified.

Guba (1990, p. 18) stated these paradigms respond to three basic questions:

“Ontological: what is the nature of the knowable? or what is the nature of ‘reality’.

Epistemological: what is the nature of the relationship between the knower (the inquirer) and the known (or the knowable).

Methodological: how should the inquirer go about finding out knowledge.”

Within these questions Taylor (2006) believes there are many approaches to generating knowledge and one kind is not necessarily superior to the other. The methodology or the theoretical underpinnings which best fits the research purpose incorporates the ontological and epistemological paradigms which reflect the research aims and objectives. Morse and Field (1996) maintain the approach chosen for a research study is dependent on the type of research question, the goal of the research, the nature of the phenomenon to be described, the maturity of the concept or how much is already known about the topic, the characteristics of the participants in the setting and the background knowledge of the researcher.

Silverman (2005, 2006) contends the methods only acquire meaning and vitality in their “embeddedness” in a particular theoretical perspective or methodology. The choice of methodology should reflect an overall research strategy as the methodology shapes which method is used and how each method is used (Silverman, 2005). Boyer (2004) suggests the choice of methodology is based on the researcher’s understanding of the world and the researcher is part of the methodology they choose. He believes the researcher is part of the study as “you are the one who selects what to include and what to exclude and how it is represented. You cannot step outside of yourself and pretend you are neutral” (p. 83). As Morse and Field (1996) say, “the wise researcher builds a methodological toolbox and develops a critical awareness of self and motives” (p. 12).
Taking this into account, this research aims to find new knowledge and adapt existing knowledge to the phenomenon of family member’s experience of an AYA dying of cancer. In order to address the aim it was important for me to select a methodological approach which would be suited to the sensitive nature of the research topic, addressed my position as a researcher and mother of an adolescent who had died of cancer, and provide appropriate methods to achieve the research objectives. This study is not seeking to deconstruct the experience for the participants associated with the research paradigms to the right of the break, but rather to give voice to the experience of the family members in the study.

**Justification for Narrative Inquiry**

Two of the four research paradigms that may answer the ontological, epistemological and methodological questions for this study are the interpretive and critical paradigms. Weaver and Olson (2006) conducted an integrative review of the literature describing the various paradigms in nursing research and identified the contributions of researchers to these two paradigms. They identified interpretive research as qualitative methodology that is used to gain in-depth descriptions, understandings and explanation of experiences and critical research as concerned with raising awareness of social problems and ensuring the voices of marginalised people are heard.

In support of critical research Fraser (2004) argues qualitative research is escapist, if it ignores sociopolitical phenomena and tends to support the social structure. She believes research should not only reflect reality, but challenge taken for granted assumptions. Thus, Fraser expounds a critical social science view of epistemology. However, Weaver and Olson (2006) argue that limitations to critical research include an emphasis on rationality, while excluding feelings. They argue the researchers are part of the culture they are critiquing, and that valuing the collective over the individual may exclude individuals at a personal level and researchers may suppress findings incompatible with their beliefs.

Whilst the experiences of the family members in this study may influence future socio-political decisions, it is not the purpose of this study to focus on socio-political change but rather to understand the experiences of the family members in the study. In addition if the focus is on socio-political change, bias may be introduced and the emotional and
personal discarded from the research process (Weaver & Olson, 2006). For these reasons this study favours the constructivist/interpretive paradigm.

The following ontological/epistemological belief systems are associated with the constructivists/interpretative paradigm; there are many truths and interpretations of reality, which are subjective and constructed. To understand the construction of reality for an individual requires subjective interaction between the individual and the researcher (Guba, 1990; Lather, 2006). The methodological process is hermeneutic and dialectic. Hermeneutically the individual’s constructions are depicted as accurately as possible and then compared and contrasted dialectically with other individual constructions to create substantial consensus (Guba, 1990).

Within the interpretative paradigm is a large number of choices and approaches which have been documented in several classifications or typologies (Tesch 1990, Wolcott 1992, Miller & Crabtree 1992, Jacob 1987, Lancy1993, Denzin & Lincoln 2005 as cited in Cresswell, 2007). Creswell (2007) lists these classification systems and notes their interdisciplinary roots.

Woodgate (2000a) identified four research methodologies located within the interpretative paradigm which may be appropriate for understanding children’s perspectives of their cancer experience; grounded theory, ethnography, phenomenology and illness narratives. These four methodologies seek to arrive at an understanding of a particular phenomenon from the person experiencing the phenomenon. She believes by using one of these designs a priori theories or generalisations are not imposed and the interpretations are more a reflection of the participant and not the researcher. Grounded theory focuses on the social structure and generating a theory, ethnography focuses on cultural knowledge resulting in micro or macro ethnography, phenomenology focuses on understanding the essence of how individuals experience a particular phenomenon, whilst the illness narratives (narrative inquiry) focus on highly personalised stories of illness with recognition of biographical data of individuals (Woodgate, 2000a, p. 195).

In understanding these four interpretative frameworks in the context of the aims and objectives of this study, grounded theory with its emphasis on complex social processes with theory generation, and ethnography with its emphasis on generating a cultural description of a phenomena, were not considered appropriate. This study is focused on
understanding the experience of the participants and not generating a theory or a cultural description.

Two of the research methodologies that focus specifically on understanding the experience of a phenomenon for the participant, are the illness narratives (narrative inquiry) and interpretative phenomenology (Lindsay, 2006). Lindsay (2006) believes the ideas and language within narrative inquiry and interpretative phenomenology contain similarities and difference. The similarities relate to the “open holistic nature of experience” (Lindsay, 2006, p. 33). Phenomenological understanding as described by van Manen (1990) seeks to draw out the essential meaning of human experience and explore the lived experience of individuals. The phenomenological research approach values human perception and subjectivity and seeks to explore what an experience is like for the individual concerned. The goal of phenomenology is to describe accurately this lived experience (Morse & Field 1996). Narrative inquiry uses stories to describe human experience (Bruner, 1987; Emden, 1998a; Polkinghorne, 1988). Lindsay (2006) describes the differences between these two methods of inquiry as the phenomenon under study. She refers to phenomenology as a “fundamental ontology in which the question of the meaning of ‘being’ is the key term” (Lindsay, 2006, p. 35). On the other hand, narrative inquiry is concerned with epistemology and the reconstruction of experience in time in which meaning will change as time passes. Therefore, as Clandinin and Connelly (2000) point out, the fundamental difference is seeing things in time compared to seeing things as they are becoming. This study is attempting to reconstruct the experience of family members to learn more about the experience of an AYA family member living and dying of cancer. This reconstruction involves two distinct dimensions: episodic, the events or episodes that are connected with the experience; and configurational the process of organising these events or experiences as a temporal whole within a plot (Freeman, 1997). The study does not seek a deeper analysis of the meaning of being in this experience or to see the experience as it is becoming. Therefore, narrative inquiry was considered to be the most appropriate methodology for the research question.
The Historical Roots of Narrative Inquiry

Narrative inquiry does not fit within any scholarly field (Riessman 1993; Mishler 1995; Hyvärinen 2006). Riessman (2008) says “just as there are different ways of defining narrative, and contrasting approaches to interpretation, so too there are several histories” (p. 14).

The narrative turn began with a group of leading US scholars from various disciplines using narrative as an organising principle for understanding social life (Riessman 1993). The concept of narrative has successfully been accepted by psychology, education, social science, political thought and policy analysis, health research, law, theology and cognitive science. Riessman (2008) believes the narrative turn was the start of the social sciences moving away from discipline specific and investigator–controlled practices.

Kristen Langellier locates this narrative turn in the 1960s and suggests four movements shaped the turn:

1. critiques of the social science of positivists modes of inquiry, and their realist epistemology;
2. the “memoir boom” in literature and popular culture;
3. the new “identity movements” – emancipation efforts of people of colour, women, gays and lesbians, and other marginalized groups; and

Czarniawska (2004) believes narrative has its beginnings in the hermeneutic studies or interpretation of the Bible, Talmud and Koran. Czarniawska (2004) says much of the present linguistic and narrative analysis can be traced to two linguists, the Pole Jan Niecislaw Baudonin de Courtney (1929/1945) and the Swiss Ferdinand de Saussure (1913/1957). Roman Jakobson (linguist), Tzvetan Todorov (literary theorist) and Algirdas Greimas (semiologist) continued in France to develop this East European
tradition. Elsewhere, Mikhail Bakhtin with others continued in Russia behind the Iron Curtain (Czarniawska, 2004). Propp (1928/1968) introduced narrative, in more contemporary times with his analysis of the underlying structures of Russian fairytales.

Northrop Fry and Robert Scholes introduced the tradition of US new criticism and looked at universal plots along with the evolution of narrative history. The French narratologists, such as Tzvetan Todorov and Roland Barthes were influenced by Propp and anthropologist Claude Lévi-Strauss’s structuralism which looked for the invariable structure of the universal human mind, as did linguist Naom Chomsky (Czarniawska, 2004), whilst Hans-George Gadamer (1900/2002) extended traditional hermeneutics (Gadamer, 1960 reprinted 1975). “Hermeneutics, is an approach to the analysis of text that stresses how prior understanding and prejudices shape the interpretive process” (Denzin & Lincoln, 2005, p. 27). Gadamer (1960) argues that human beings are beings in language and we cannot understand ourselves and the world without language. As such, we are situated in a linguistically mediated, historical culture, which shapes our world view. Further to this Paul Ricoeur (1984, 1985, 1988) incorporated aspects of various schools to demonstrate the relationship between temporality and narrative.

This interest in narrative spread beyond literary theory to the humanities and social sciences. For example, historian Hayden White (1973) claimed history was historiography because events are emplotted into histories rather than finding the events. The Chicago School sociologists of the 1920s and 1930s introduced life history as a method to study sociological material (Chase, 2005). At a similar time anthropologists saw life history as a way to understand cultural facts and to present insider views of culture and daily life (Chase, 2005).

Labov and Waletzky (1967 reprinted 1997) are credited with the narrative turn into the social sciences, extended Propp’s formal analysis suggesting that socio-linguistics should be concerned with the syntactic analysis of simple narratives to understand the structure and function of more complex narratives. They define the narrative of personal experience as “a report of a sequence of events that have entered into the biography of the speaker by a sequences of clauses that correspond to the order of the original events” (Labov, 1997 p 396). Elliot (2005) indicates that despite an interest in Labov and Waletzky’s work, there are few contemporary studies, which adopt their sociolinguistic framework as a guide for analysis. Bruner (1997) claims Labov and Waletzky succeeded in blazing a trail for the study of narrative, in the social sciences, as
they provided “a cognitive representation of reality on our experience of the world and on how to evaluate that experience” (Bruner, 1997, p. 64). Despite this, Labov and Waletzky were caught up in structuralist thinking of their day and the holistic configurations of narrative were overlooked (Bruner, 1997). Holmes (1997) argues the interpretation of language text and context is neglected in Labov and Waletzky’s model.

This is verified by Riessman (1997) who found, in her study on divorce, that some of the long stretches of talk were unanalysable using Labov and Waletzky’s model. She noticed that “crucial meanings are lost if the form of telling is ignored, and the text is fragmented and decontextualised” (Riessman, 1997 p 157). Freeman (1997) further stated that the process of narrative involves the configuration of happenings and events as a temporal whole, organised around a plot to discern patterns and constellations of meaning and not in terms of succession of disconnected events. Added to this Edwards (1997) argues this tends to obscure specific detail, which is crucial for a deeper understanding of the story. There is a danger that analysis may objectify the subject if we do not allow for the diversity of narrative form and diverse ways of telling (Edwards, 1997).

As such, Elliot (2006) argues that Labov and Waletzky’s model may be useful for analysing short sections of narrative interviews, but it has less utility when examining a narrative interview more holistically.

Despite these concerns, by the end of the 1970s the narrative turn was well underway with narrative inquiry a methodology embraced by many disciplines in the humanities and social sciences. The interest in narrative, by various disciplines resulted in narrative as a methodology, considering other models outside the reductionist methods of Labov and Waletzky, with a greater emphasis on individual narratives and story.

For example the 1980s saw narrative embraced by women’s studies (Riessman, 2008). Interpreting Women’s Lives appeared in 1989 edited by the Personal Narratives Group to indicate the solidarity of a cross disciplinary intellectual movement. Narrative was seen to focus on narrator – interpreter relations, context and narrative form rather than the representation of the female as a subject from a distant standpoint (Riessman, 2008). Labov and Waletzky’s sociolinguistic theory and work in conversational analysis led Mishler to the theory of the open-ended interview as a narrative event. This paved the way to the introduction of narrative into psychology in the 1980s with the contribution
of Sarbin (1986), Bruner (1986) and Polkinghorne (1988). The emphasis was on the creation of meaning, through storytelling and the development of a holistic story creating a metaphor for the experience (Hyvärinen, 2006).

This brief history of the roots of narrative inquiry is complicated by the fact that there is no single text or discipline that has inspired all authors. Hyvärinen (2006) with a limited survey of the sources of inspiration for the early narrative turn authors, confirms only a few key authors of the narrative turn have discussed the ideas of literary narrative theory. These include philosopher Paul Ricoeur (1984; 1985; 1988) and psychologists Donald Polkinghorne (1988) and Jerome Bruner (1986). Whist Mark Freeman (1993) draws on Jean-Paul Sartre and St Augustine and a number of literary theorists, his major theoretical ideas are from philosopher Paul Ricoeur and anthropologist Clifford Geertz (1973). Dan McAdams (1988) draws on psychologist Erik Erikson’s work on identity and biological studies in sociology and literature and rarely refers to literary theory of narrative. For Mishler (1986), the source is the contemporary socio-linguistics of Labov and Waletzky (1967). In addition, Mishler (1986) like Bruner (1986) and Freeman (1993) incorporate discussions of narrative in psychoanalysis (Hyvärinen, 2006). Further, the theme on personal narration stems from anthropology, feminist studies, and sociological studies of autobiography (Hyvärinen, 2006). Prominent in the field of narrative inquiry is Ricoeur (1984, 1985, 1988) who examined narrative in great depth, from philosophy to literature and historiography, but was unable to cover the whole field of narrative inquiry excluding the sociolinguistic form. In contrast Carr (1986) introduced a phenomenological view in which narrative grows from human experience and action. He stated the structure belongs not just with the narration or language but also to human events, experience and action.

Therefore, narrative seems to sprout from numerous discrete locations and no homogeneity of heritage exists within narrative inquiry (Hyvärinen, 2006). Hyvärinen (2006) contends the issue in narrative is not about the source of the complementary and competing theories of narrative, but about how these theories evolved. She believes one of the reasons for the evolution was the metaphor of narrative, which provided scholars with a more complex and less objectivistic form of knowing than the previous laws, experiments and abstract theories. For example, in MacIntyre’s (1984) classical introduction to the narrative as identity and the metaphor of living out narrative, there is no mention of literary or socio-linguistic theories on narrative. Hyvärinen (2006, p. 26)
concludes, “the concept of narrative thus does not travel from literary theory; it enters the discussion as an everyday term”.

MacIntyre’s (2004) contribution to narrative resulted in expanding the range of reference to narrative. This is evident in the narrative turn in psychology (Bruner, 1987; Polkinghorne, 1988; Sarbin, 1986) where the individual’s story is the answer to the question and the story is the metaphor for experience. This emphasis on story has provided a “new heuristic perspective of life, psychology, identity and action” (Hyvärinen, 2006, p. 32). The stories become idiographic in orientation, the primary unit of analysis is the individual life (Freeman, 1997). Therefore, the narrative turn in literature focuses more on the content of the stories rather than the form (Hyvärinen, 2006). This resulted in narratives having the potential to integrate human lives and for healing and benevolent narratives to be generated (Hyvärinen, 2006).

From this discussion on the roots of narrative theory it can be difficult to determine where contemporary narrative has its classic roots. The beginnings of narrative in the human sciences are contested, whilst there are taproots in a variety of disciplines which inform narrative inquiry (Riessman 2008). Riessman (2008) says narrative analysis relies on diverse theories and epistemologies. Since Labov and Waletzey’s (1967) introduction of socio-linguists method of analysis that introduced narrative into the social sciences, theories have tended to focus on the individual story and are not rooted in the classical structural linguistic theories of reduction of the text to individual language components.

This study is concerned with an individual’s story of the phenomenon under study. Therefore, this study will focus on contemporary narrative theory and theorists to establish what epistemological and ontological assumptions from the theories could best be applied to the stories of the experience of an AYA family member living and dying of cancer.

**Narrative as Storytelling**

Narrative inquiry uses stories to describe human experience (Bruner 1987; Emden 1998a; Polkinghorne 1988). Stories or narratives determine how we understand our own and others life. Bruner (1987) says stories are constructed in people’s heads. These
constructed stories can direct the author’s life, as “we become the autobiographical narratives by which we tell about our lives” (Bruner, 1987, p. 15). Sarbin (1986) calls this the narratory principle: “in that human beings think, perceive, imagine and make moral choices according to narrative structures” (p. 8). He believes a historical event is the root metaphor in peoples’ understanding of the world or in other words how people make sense of the world. The stories of a historical event provide the context for reasons people act, as well as the causes of happenings (Sarbin, 1986). Therefore stories as constructed by the author give meaning to people’s experience (Emden, 1998a; Frank, 1997; Kleinman, 1988). Frank (1997) expands this further, believing stories of suffering produce a testimony of the person’s lived experience which can facilitate healing.

These stories can only be told if the person is given the opportunity and the time to create them. Stories are solicited by simply asking the interviewee to tell how something happened. People do not have to be taught how to tell stories because it is a way we make sense of and communicate life episodes (Polkinghorne, 1995).

Narrative inquiry has the potential to provide the context for the stories to be told. In narrative inquiry, as Emden (1998b) suggests, the interview should be approached with the intent of hearing stories. Narrative has a commitment to the value of giving voice to human feelings and experience (Redwood, 1999), through the use of “imaginative reconstruction” or “empathy” (Elliot, 2005). Grinyer (2002a) believes narrative is an appropriate method for sensitive research as it allows family members to determine the content of the information they share which she sees as strength rather than a weakness.

Due to this sensitive research topic and the desire to avoid psychological harm from the telling of a painful story, the following explains my ethical reasons for choosing narrative inquiry to hear the family members’ stories. Family members will have the opportunity to tell of their experience that gives a voice to the experience and has the potential to create meaning and possible healing from the painful stories. This is facilitated by empathic listening, providing an occasion for the family members to create a testament of the story of an AYA dying of cancer. It also allows the family member to construct the story in their own time and in their own terms, lessening the likelihood of psychological harm as the family member is less likely to speak of events which, at that particular point in time, they may find too difficult to accommodate.
In further support of narrative inquiry and my own experience of my son dying of cancer is the concept of a shared reality. Bruner (1987, p. 21) has said that “life stories must mesh … tellers and listeners must share some ‘deep structures’ about the nature of a ‘life’”. If this does not occur both the storyteller and the listener will fail to grasp what the other is telling or hearing. Thus, narrative inquiry takes account of my own story, and due to this experience I can more fully grasp the family member’s story through possible shared meaning, providing a richer understanding of the stories being told.

Narrative Inquiry therefore is a suitable methodology for this research study. Within its epistemology, understanding is the development of knowledge through the telling of stories. These stories create meaning and a possible testament of the experience, giving voice to what might not be told. The methodology suggests my own experience, rather than hindering the research, creates the context for me as the researcher to grasp what the family member is saying. This shared experience with the family member has the potential to create a more empathic understanding of the story.

**Contemporary Narrative Inquiry**

Given that no homogeneity of heritage exists within narrative inquiry, as discussed in the section on the historical roots of narrative, it stands to reason that “[t]here is considerable disagreement as [to] the precise definition of narrative” (Riessman, 1993, p. 17). Even the terms used to describe what researchers study have flexible meanings (Chase, 2005). Therefore, the definition of narrative requires consideration of the multiplicity of narrative inquiry. Chase (2005, p. 651) defined contemporary narrative inquiry as “an amalgam of interdisciplinary analytical lenses, diverse disciplinary approaches, and both traditional and innovative methods – all revolving around an interest in biographical particulars as narrated by the one who lives them”. Within this broad definition of narrative is the distinction between narrative and story. Polkinghorne (1988, p. 16) differentiated between a story and a narrative, by asserting that “a story is a single account, reviewing life events in a true or imagined form”. Stories are the way humans make sense of the world, in that we learn about who we are, our history, and our culture (Shankar & Goulding, 2001). Telling stories is universal, as people make sense of an experience by storytelling. People create plots from disordered experience in order to make sense of the experience (Riessman, 1993). Therefore, stories make our lives and ourselves intelligible to ourselves and others (Gergen &
Gergen, 1986). On the other hand, a narrative is a scheme of multiple stories “that organise events and human actions into a whole” (Polkinghorne, 1988, p. 18) expressed in story form (Polkinghorne, 1988). Parker & Wiltshire (2003) contend that narrative is concerned with the shaping of stories through reflection, the development of a conceptual structure and with an ethical element. “Narrative, then, normally involves the uncovering or creation of meaning within experience” (Parker & Wiltshire, 2003, p. 101) through the stories that people tell. In other words the phenomenon under study is the story and the interpretation is the narrative (Clandinin & Connelly, 2000). Therefore, narrative inquiry takes as the object of investigation the story itself (Emden, 1998a; Riessman, 1993). Within this broad understanding there exists different interpretations of the true nature of narrative inquiry.

Despite this there appears to be some level of consensus on the nature of narrative. Narrative has been described as stories with temporal sequence of a beginning, a middle and an end (Riessman, 1993; Sarbin, 1986; Shankar & Goulding, 2001). This sequence of events can be understood in relation to the whole (Elliot, 2005; Polkinghorne, 1988). The narrative conveys the complete and integrated meaning of the life event (Elliot, 2005). Elliot (2005) sums up the key features of narrative as temporal, meaningful and inherently social. These features cannot be understood as totally independent, as the meaning of an event within a narrative depends on the temporal sequencing and the social context in which the story is told (Elliot, 2005). This concept of social context is expanded on by Clandinn and Connelly (2000) and Redwood (1999); the former who emphasise the personal and social interaction and place of the narrative, with the latter highlighting the dimension of plot and the voice of the researcher.

As Riessman (2002, p. 697) suggests:

> storytelling is a relational activity that encourages others to listen, to share, and to empathise. It is a collaborative practice and assumes that tellers and listeners/questioners interact in particular cultural milieus and historical contexts, which are essential for interpretation.

Essential to the understanding of narrative is the concept of plot. The narrative is a way of organising episodes, actions and accounts of actions; it is an achievement that brings together mundane facts and fantastic creations; time and place are incorporated. The narrative allows for the inclusion of actors’ reasons for their acts, as well as the causes
of happenings (Sarbin, 1986 p 9). Sarbin (1986) believes the plot is the structure that organises and gives meaning to these experiences. This structure is the form in which the narrative is created whilst meaning is the storyteller’s interpretation of what is happening (Pellico & Chinn, 2007). In other words the narrative analysis method for this study will provide the structure for the plot or narrative whilst the interpretation of the stories told will reveal the meaning of the stories.

Gergen and Gergen (1986) suggest the elements that guide our construction of a narrative or a plot are: the construction of a valued end point; the selection of events to achieve that end point; the arrangement of events to achieve that end point, usually placed in a linear, temporal sequence; the establishment of causal links to the events and demarcation signs; and a beginning, a middle and an end. Given these elements in the construction of the narrative, there are three prototypical narrative forms, (i) progressive or movement towards the goal, (ii) regressive or movement away from the goal and (iii) stability, where events produce no change towards the goal. Gergen and Gergen (1986) state these three prototypes exclude the narrative form of dramatic engagement, or the capacity of narrative to create feelings of drama or emotion.

Two characteristics appear significant for dramatic engagement, these being alteration and acceleration in the opposite direction from the previous goal state. This alteration and acceleration in the opposite direction can be viewed as a life transition where “people choose to make changes in their lives, or make changes in their experiences of their lives in response to external events” (McAdams, Josselson, & Lieblich, 2001, p. xvi). Denzin (1970) refers to these transformational experiences as epiphanies, because after these turning points, the person will never be quite the same. Life transitions become meaningful only when articulated and given meaning, in retrospect. These life transitions are remembered and told time and time again and they are given a thick description in personal stories and are brought alive with all the density of emotion and interaction (Löyttyniemi, 2001). In studying people’s stories, readers can begin to understand the meaning of these transitions (McAdams, et al., 2001).

Gergen and Gergen’s (1986) description on the construction of a narrative provides some guidance on how to create a narrative for the purpose of this research. Of particular interest for this research topic is the concept of life transitions where people make changes to their life as a result of an external event or, as Denzin (1970) describes them, an epiphany. The life changing transition of having an AYA being diagnosed and
eventually dying of cancer is definitely an alteration and acceleration from a previous goal state. It is thought that by telling the stories the family member may be able to create some meaning from this life changing experience. This is supported by Kleinmann’s (1988), Frank’s (1995) and Hyden’s (1997) illness narratives described in this chapter.

Further to Gergen and Gergen’s (1986) elements to guide construction of a narrative, Bruner (1987) introduces the notion of narrative truth. He talks about the construction of a narrative demonstrating the difference of a life as lived (what actually happened), a life as experienced (the images, feelings, desires, thoughts, and meanings known to the person whose life it is), and a life as told (a narrative). Therefore, narrative is the person’s representation of the life as lived and experienced. Narrative “truth” is distinguished by a life-like, intelligible and plausible story. The narrator strives for “narrative probability – a story that makes sense; narrative fidelity – a story consistent with past experiences or other stories; and aesthetic finality – a story with satisfactory closure and representational appeal” (Sandelowski, 1991, p. 165). Stories are constructed memories as representations of events at that moment in time. Stories can change from each telling “making the idea of empirically validating them for consistency or stability completely alien to the concept of narrative truth” (Sandelowski, 1991, p. 165). These elements of narrative truth have the potential to be the standards by which the research rigour can be judged and is discussed in more detail in the methods chapter.

The task of interpretation does not mean we understand or know the person. The interview only has the meaning ascribed to it by the listener. Understanding means relating the person’s words as a personal truth of the person, which we can never completely reach. We can never know the other fully, but only imagine what the other might be. Therefore, the interview is given meaning, not through the narrator, but the people, who will listen to the words and take them seriously (Löytyniemi, 2001). Löytyniemi (2001, p. 200) contends that “it is the listener, who either allows or denies the narrator coherence and personal change”.

Therefore, when constructing the narrative for this study, regardless of the method chosen there was a requirement to be mindful that the stories told were representations for the family member at that particular point in time. The stories told are interpreted and given meaning through my own understanding of these stories. This is influenced
by my understanding of the phenomenon under study and an ability to connect empathically with the person. For this study this understanding is related to my own story, in addition to the knowledge and experience that I bring to the study, which is explored in more detail in the chapter on methods.

In summary, although authors’ views of narrative differ according to their particular world views and purposes, there is agreement in the literature that the meaning of a narrative is constructed through social discourse, in that the person makes links between aspects of the life he or she is living and their understanding of those aspects through stories. The role of myself as reader is “to connect this understanding with some form of conceptual interpretation, which is meaning constructed at another level of analysis” (McAdams, et al., 2001, p. xii). This construction involves temporally ordering aspects of a story into a plot to create structure and meaning. Narrative provides the opportunity for people to make sense of life changing experiences or epiphanies. Within this understanding is the concept of narrative truth that is a life-like, intelligible and plausible story based on a person’s representation of the experience at that particular time. Narrative’s attention to story, its ability to create meaning out of the experience and its emphasis on transitional periods in people’s life as a methodology is suited to the topic of research in this study. In this context the stories in this study are the stories of family members as told to me and the narrative is my reflections on the stories using narrative analysis to interpret the stories at another level. To provide further support for the use of narrative within the context of this study, the next section provides support to the use of narrative within the health field and in particular the use of narrative to create meaning from the cancer journey.

**Health Research and Narrative Inquiry**

To further support the decision to use narrative inquiry as the methodology for this study, the application of narrative inquiry to research within the health sciences and nursing is reviewed.

Stuhlmiller & Thorsen (1997) believe understanding a person’s narrative is important for academics, researchers and clinicians, as you gain insight into the human experience. The use of narrative within the health professions has been identified as providing a greater understanding of the illness experience (Frank, 1997; Kleinman,
1988; Mattingly, 1994; Mishler, 1986a, 1986b). Emden refers to Sandelowski’s (1991) and Boykin and Schenhofer’s (1991) support of the use of narrative within the context of nursing research (Emden, 1998a). The turn to narrative asks researchers to view respondents as narrators and interview data as stories (Emden, 1998a) as this fits well with people’s natural inclination to tell and listen to stories. The illness narratives have an application in understanding the cancer journey (Overcash, 2004), because “narrative can provide insight on human interactions, social moral conduct, perceived role responsibility, and other perspectives integrated into a coexistence with the diagnosis of cancer” (Overcash, 2004, p. 180).

Overcash (2004) reviewed the literature from psychology, sociology, anthropology and nursing to establish a case for narrative as a viable methodology for nursing. She discussed narrative within the context of the interview and the illness narratives. She concluded that nurses have the skill of active listening and narrative research can help enhance both patient care and clinical practice. As Sandelowski claims, a “narrative framework affords nursing scholars a special access to the human experience of time, order and change and it obligates us to listen to the human impulse to tell tales” (1991, p. 165).

**Narrative in the Health Sciences**

Narrative has been advocated in the health sciences as a qualitative method to advance knowledge and practice in the following areas: occupational therapy (Mattingly, 1994), medical education (Bleakley, 2005), interdisciplinary research in education and nursing (McQueen & Zimmerman, 2006), health promotion (Riley & Hawe, 2005) and pharmacy (Bissell, Ryan, & Morecroft, 2006; Ryan, Bissell, & Morecroft, 2007).

**Narratives in Nursing**

There are many examples of narrative research in nursing and researchers have used creative means to undertake data analysis. Emden (1998a, 1998b), McCance, McKenna & Boore (2001), Kelly and Howie (2007), Aranda and Street (2000) have conducted research in nursing involving narrative inquiry. Emden (1998a,b) focused on nursing scholars and scholarship, McCance et al (2001) focused on nurses’ and patients’ experience of caring, whilst Kellie & Howie (2007) explored how training in Gestalt therapy influenced psychiatric nursing practice.
ILLNESS NARRATIVE IN NURSING AND THE HEALTH SCIENCES

The use of narrative can inform and provide insight into practice. Of particular interest in this PhD study are the illness narratives, which include Bailey and Tilley (2002), who considered the experience of patients, families, caregivers and nurses during an acute dyspnoeic attack in individuals living with chronic obstructive pulmonary disease. Other examples of illness narratives of interest are Blumereich (2004), who used a post structural critique of narrative as a guide to create illness narratives of children with HIV, and Bradway (2005), who used narrative analysis to develop an understanding of the experience of longterm urinary incontinence. In addition, Docherty and McColl (2003) and Lee and Poole (2005) analysed chronic illness narratives, discovering how people living with a chronic illness can create meaning out of the experience.

Further to this is Aranda and Street’s (2001) study explored the relationships nurses developed with patients in response to the patients’ suffering from a life threatening or terminal illness. The nurses told stories of their experience of nurse-patient friendship. Also Kennedy, Shannon, Chuahorn & Kravetz (2004) conducted a narrative analysis to develop an understanding of the processes of care and beliefs, which are central to midwifery practice. Narrative was chosen for this study as it “creates paths to solve clinical problems, provides a voice to clients and nurses, informs social policy, and addresses diversity through understanding” (Kennedy, et al., 2004, p. 15). Robichaux & Clark (2006) used narrative analysis to explore the actions taken by critical care nurses, who thought aggressive medical intervention was not warranted in end of life care. The narrative plots emerged of “protecting or speaking for the patient, presenting a realistic picture and experiencing frustration and resignation” (Robichaux & Clark, 2006, p. 480).

Katz and Mishler (2003) provide a good introduction to the illness narratives with exemplars from medicine and health care. The exemplars provide an understanding of how illness is interpreted within the health care system for both the clinician and the patient. In a different research context, Rich and Grey’s (2003) narrative analysis of survivors of penetrating wounds highlights the central role of health providers in managing these patients’ fear of death. These examples of the illness narratives within nursing and health care provide illustrations of the application and suitability of
narrative within this area of research. Central to this PhD study is the use of the illness narratives within the context of the cancer journey.

**Cancer Narratives**

Overcash (2004) in her summary of the benefit of narrative inquiry, supported the illness narrative of cancer to enhance clinical practice. She also recognised the benefits for the participant or cancer sufferer. She claimed that the illness narrative allows the experience of the cancer journey to be understood by others, it is therapeutic and it gives voice to an experience that cannot be explained through medical discourse. Narrative research has also provided a forum for caregivers to express the burden of care-giving, facilitating health care providers to address these issues. Narrative research is also useful in helping patients cope with the illness, before a crisis may develop. For example, in studies with patients with head and neck cancer who had cosmetic surgery, narrative was beneficial in exploring the quality of patients’ interpersonal relationships and its influence on coping strategies. Narrative was also beneficial for women who had breast cancer by examining the experience of support groups for these people. (Overcash, 2004). Finally, Overcash (2004) asserts that narrative can act as a medium to provide culturally relevant care, as demonstrated in the narrative of an immigrant Cambodian family whose adolescent child died.

Mathieson and Stam (1995), previously mentioned in Chapter Two, used the concept of identity to reframe the psychosocial issues of cancer. The authors argue that patients create meaning out of their experience through narrative conceptualisation. The authors advocated the use of narrative, as the narrative maintains the patient’s context and provides a testimony of the illness - not a scientific interpretation of the illness. They concluded that the narrative views “the culture of the illness from the lives of the ill, rather than from the perspectives of the researcher or the medical system … For the ill, this sense of innovation in self-understanding is crucial to a life that is circumscribed by social and bodily limitation” (Mathieson & Stam, 1995, p. 302).

Good, Munakata, Kobayashi Mattingly and Good (1994) employ Mattingly’s concept of therapeutic emplotment to create therapeutic stories related to the treatment of cancer and the cancer journey. The authors interviewed and observed North American surgical,
medical and radiation oncologists and noted how they seek to emplot experiences to install hope in the patient.

Mcilfatrick, Sullivan and McKenna (2006) and Mcilfatrick, Sullivan, McKenna and Parahoo (2007) used narrative analysis, to explore the experience of chemotherapy in a day hospital setting. The caregiver’s narrative (Mcilfatrick et al, 2006) included exploring the transition from the inpatient unit to the day hospital. The themes that emerged from the caregiver’s and patient’s experience of the diagnosis and feelings about treatment, revealed emotions of shock, devastation and fear (Mcilfatrick et al, 2006, Mcilfatrick et al 2007) further reinforcing the use of narrative to provide a deeper understanding of the cancer experience.

Woodgate (2006b) further developed the use of narrative in the understanding of childhood cancer from the child and family perspectives. Woodgate (2006b, p. 16) concluded that narrative inquiry enabled the children and their families “to construct and understand their changing way of life.” The stories were seen as providing an expression of the cancer experience, distinct from the biomedical model, and of developing an understanding of the suffering experiences related to the increased stress and psychosocial concerns of children and their families with cancer. In addition Woodgate and Degner’s (2004) study provided a new perspective in understanding childhood cancer and assisted in understanding and developing symptom relief strategies.

DEATH AND DYING NARRATIVES

The illness and cancer narratives have also been extended to research in thanatology, which is research with the dying and the bereaved (Carverhill, 2002; Gilbert, 2002). A recent article reviewed and described a number of narrative analysis approaches that may be used in palliative care (Bingley, Thomas, Brown, Reeve, & Payne, 2008). The authors concluded “palliative care clinicians and researchers have the opportunity to build on a wide range of narrative research methods with the potential to inform and improve health care policy, medical and health science training and practice” (Bingley, et al., 2008, p. 657). Of particular interest for this study was how the family members make sense of death and dying.
Thomas et al (2009) demonstrated the utility of narrative in thanatology in their study in England of two terminally ill patients and their spouses, through a series of semi-structured interviews during the last few weeks of the patients’ life. The authors contended that through the use of storytelling the patients’ and carers’ self identities, perceived illness state and symptoms, and their care related needs, behaviours and desires could be explored. The authors conclude “that the use of narrative methods in a clinical context with individual patients has the potential to develop a necessary evidence base to further support the clinical care of individuals with complex and multifaceted identities” (Thomas et al, 2009, p. 795) and represent a valuable addition to research in palliative care.

Abma (2005) presented a case study of a husband of a terminally ill patient and interviews of two nurses caring for the patient. The case study revealed that the husband’s narrative of depression, social isolation and loss of hope was not heard by the two nurses interviewed in this study. From this case study, Abma (2005) advocated the development of a relational narrative approach as a theoretical framework to understand emotional and existential problems of patients in care. The relational narrative provides ethical knowledge, which is co-created by the nurse and the patient.

Fins et al (2000) used narrative analysis to interpret the deaths of 200 patients through audits of their medical records. They conclude “research on narratives can help script more emphatic and compassionate care of the dying by demonstrating that every death is a story waiting to be told” (Fins, et al., 2000, p. 399).

Carter, Macleod, Brander, and McPherson (2004) used a combination of narrative analysis and grounded theory to explore what the patients perceived as their priorities in living with a terminal illness. The issue of central concern for the participants was ‘taking charge’, in which dying patients plan an active role in their care. This included “identifying and fulfilling their needs related to symptom management and life functioning and … determining and realising their philosophical positions about the meaning of life in the face of death” (Carter, et al., 2004, p. 614). The authors concluded that understanding a patient’s perspective could result in management strategies tailored to the individual patient’s needs.

A narrative study of relevance in my study, discussed in the literature review, involved the stories of children and young people with advanced or terminal illness.
Chantelle’s study concluded “that respect and compassion for adolescents involves a series of challenges” (Chantelle, 2004, p. 285). She says that their voices “deserve to be heard in conversations about life and death, as hard as they may be for all of us. From the youngest among us comes sage wisdom about unthinkable life events” (Chantelle, 2004, p. 285). The narrative method gave voice to these young people, whose stories can be ignored in normal conversation (Chantelle, 2004).

The study by Chantelle (2004) invited participants to tell the story of suffering of the family and the AYA who was dying. Prominent in this field is the work of Anne Grinyer whose research is discussed in more detail in Chapter Two (Grinyer, 2002a, 2004b, 2006a, 2006b, 2007a, 2007b, 2008; Grinyer & Thomas, 2001). Grinyer used narrative to enable participants to tell the story of the cancer experience of AYAs, from the parents’ perspectives (Grinyer, 2002a, 2004b, 2006a, 2008; Grinyer & Thomas, 2001) and the AYAs’ perspectives (Grinyer, 2007a, 2007b). From these studies a paper was developed which contrasted the parents’ and young persons’ perspectives (Grinyer, 2009). Grinyer (2002a) advocated the use of storytelling or narrative inquiry as it allows people to impart information about their experience in their own terms and their own time. The method allows the participants to dictate the content of the information they share to a greater degree than is possible in most other types of social research, which is a strength rather than a weakness in this research context.

The stories of suffering in Grinyer’s (2002a, 2008) study of parents whose son or daughter had died, gave voice to the parent’s child, who could no longer tell their own story (Grinyer, 2006b). As a result of the research from the parent’s perspective, Grinyer (2006b) made the following observations from the stories where the AYA had died. Narrative has the potential to be therapeutic. Death talk, particularly the death of an AYA in society, is still a taboo subject. Through narrative the person who has died can live on, in the telling of the story a continuing bond can be established. Also, future publications “act as a lasting tribute and validate the participant’s experience” (Grinyer, 2006b, p. 219).

This section provides further support for the use of narrative in the sensitive and often unspoken human experience of death and dying. As seen in the examples of narrative research discussed, narrative inquiry has the potential to create greater understanding of the experience of the cancer journey for participants and researchers. In particular,
narrative inquiry is a valid method in understanding the cancer narratives of suffering and has an application in the stories of death and dying.

**Summary: Narratives Research in the Health Sciences**

The examples of narrative research discussed above demonstrate the application of narrative inquiry within the health sciences and nursing. Added to this, is the potential narrative inquiry has to create greater understanding of the experience of the cancer journey for participants and researchers. In particular, narrative inquiry is a valid method in understanding the cancer narratives of suffering and has an application in the stories of death and dying.

**CONCLUSION**

Gilbert (2002) has a message outside her office “We live in Stories, not Statistics”, because stories create the life in which we live (Freeman, 1997). Stories are “part and parcel of being in time and using language to bind experience into a sensible form” (Freeman, 1997, p. 175). The telling of stories provides opportunities for empathic understanding of the lived experience of others (Koch, 1998). The interpretive method applied to narrative has, as its base, the search for meaning (Freeman, 1997).

Carson and Fairbairn (2002) and Fairbairn and Carson (2002) further argue storytelling should be central to any research involving human life and human wellbeing, as this type of research should be about helping people.

Narrative analysis develops themes, which cannot be described in quantitative studies, and it creates an environment for the uncovering of unexplored themes, which enrich our understanding of the experience of the participant (Fins, et al., 2000). Because of the open-ended research method, participants can determine what elements of the experience to incorporate into their narratives (Grinyer 2002a). Narrative research, as discussed in this chapter, has the potential to be therapeutic and enable the participant to give voice to their story. It has been described as more reflective and respectful, as it involves listening to the participant’s story and version of events (Carson & Fairbairn, 2002). For this reason Carson and Fairbairn (2002) and Fairbairn and Carson (2002)
content that narrative is an ethically aware research methodology. For example, Grinyer (2002a) provided reflections from Geoff, who set up a George Easton Memorial Trust Fund with his wife Helen, for research into AYA’s with cancer, after the death of their 23 old son, George, from bone cancer. Geoff commented that during the cancer journey the books that were most helpful, were those written by people who had had a similar experience as their own. He further observed that the majority of research related to cancer and its treatment were through questionnaires, allowing the respondents little freedom to express their views or feelings. He believed it could be seen as unethical to have a tick of a box determine what one is experiencing through the cancer journey. “The experience of having a young adult child fall ill with cancer can only be communicated by evoking the emotions as well as the logic. It should involve feelings as well as numbers” (Geoff as cited in Grinyer, 2002a, p. 168).

Therefore, narrative was the methodology of choice for this study, because of the sensitive nature of the research topic and its proven application in stories of suffering. The justification for such a method was that it gives voice to those “whose experience would otherwise remain undocumented and unheard” (Grinyer, 2002a, p. 170). Narrative inquiry also lends itself to me, as a mother and as a researcher having lived through a similar experience, to have a greater depth of understanding and empathy for the participants. The opportunity to tell the story of cancer death and dying to someone who knows can result in a richer description of the story. Having lived the experience, I have the capacity to take on the role of ‘the other’ and to develop a more empathic understanding. The analysis provides an opportunity to respect the person’s story and produce a testimony to the young person who died of cancer and their family, thereby providing an opportunity for the story to continue to be told.

The next chapter describes the methods and processes that were used to apply narrative analysis to the family members’ stories. Included in this is the ethics approval process, the assumptions associated with narrative inquiry and the trustworthiness of the study.
CHAPTER FOUR: RESEARCH METHODS AND DESIGN PROCESSES

The creation of stories.

“There are no rules in writing. There are useful principles. Throw them away when they're not useful. But always know what you're throwing away.”

Will Shetterly

(https://koti.mbnet.fi/pasenka/quotes/q-wrtwrit.htm#Some%20words%20of%20advice)

INTRODUCTION

This chapter introduces the reader to the method and processes that were used to conduct this research study, including the assumptions related to narrative inquiry, in contrast to the empirical research context. In order to justify the use of narrative as the method of analysis for this study, the methodology of narrative inquiry is revisited briefly. To ensure that the study considered the safety of the family members and myself, the ethical approval process is discussed. This ethical approval process considers in-depth how my experience and knowledge facilitated the study whilst still ensuring the family members’ stories were told and retold with integrity. Models of narrative analysis that may be suited to this study are explored and a rationale for how they guided this study is provided. The research design is discussed, which includes the recruitment of family members, the interview process or data collection and the method of data analysis. Finally, the limitations of narrative inquiry are discussed and trustworthiness or validity of the study are considered within the limitations of this study. In summary twenty-six people self selected, through the media to tell their story individually, or as a couple or family. Each had a family member aged 12-21 who had lived and died of cancer over twelve months previously. The stories were prompted by open ended interview questions. The analysis and interpretation involved the development, of core stories, by the configuration and emplotment of the family
members’ experience of events, from the transcripts. Following this, themes were identified through Taylor’s (2006) computer-assisted thematic analysis that were further organised and coded using the NVivo8 computer software to identify commonalities and differences within the themes.

**Narrative Inquiry Within the Research Context**

This section seeks to explain the assumptions that underpin the methods and processes of narrative inquiry in contrast to the assumptions of the positivistic paradigm. The empirical assumptions of reliability, objectivity, generalisibility and validity are challenged within the context of some of the major assumptions of narrative inquiry. The narrative assumptions consider all research is language and study the connectedness of a story. The focus is on the relatedness of the researcher and the participant with a focus on the particular, and an emphasis on the trustworthiness as validity rather than the positivistic assumption of validity.

Pinnegar and Daynes (2006) discuss how the narrative turn challenges four important empirical assumptions: the assumption of reliability; objectivity; generalisability; and finally, the positivistic assumption of validity. The assumption of reliability presupposes social factors can be treated as things, which can be numbered and measured. This language of numbers is basic to empirical knowing, applying the criteria of statistical inference and probability to the research hypotheses to ensure the reliability of the research study (Pinnegar & Daynes, 2006). In contrast, narrative presupposes that all research is language and narrative researchers study the “connectedness and coherence of the extended discourse of the story entwined with exposition, argumentation, and description” (Pinnegar & Daynes, 2006, p. 29).

The second assumption of objectivity presupposes that research is a neutral activity and the subject being studied is a thing and separate and not connected to the researcher. Narrative challenges this assumption by asserting that no study is neutral, in that researchers choose to study areas based on their own curiosity and interest in the topic, involving the researchers’ passions, caring and insights. Narrative extends this concept of non-neutrality and objectivity by claiming that “knowing other people and their interactions is always a relational process that ultimately involves caring for, curiosity, interest, passion and change” (Pinnegar & Daynes, 2006, p. 29).
The third assumption, generalisability, presumes that certain research designs can remove the impact of particular cases and the study can be generalised to other settings. This is done through the scientific research process of controlled treatments, randomisation and controlling the variables of the study (Pinnegar & Daynes, 2006). “This assumption dismisses the value of the local and particular, in favour of the power of prediction and control provided by the universal” (Pinnegar & Daynes, 2006, p. 29). Narrative researchers argue that an in-depth understanding of the particular forms an important basis for understanding the individual and our interaction and relationships with others. This in-depth understanding can provide the basis for valuable and insightful action in virtually all settings, increasing our understanding of human culture and personal interaction (Pinnegar & Daynes, 2006).

Finally, the fourth assumption involves the positivistic conception of validity, anchored in objective research designs with reliable, numerical measurements, where settings can be controlled or manipulated, resulting in the generalisibility of the research findings. Narrative researchers argue this concept of validity denies other ways of knowing and insists on a single kind of truth or belief. Validity, as it relates to narrative inquiry, is the desire to understand rather than control and predict the world (Pinnegar & Daynes, 2006). The validity of narrative research is concerned with the trustworthiness of the research study, or its acceptance within the research community. As Mishler (1990) explains “focusing on trustworthiness rather than truth displaces validation from its traditional location in a presumably objective, non-reactive, and neutral reality and moves it to the social world - a world constructed in and through our discourse, and actions, through praxis” (p. 420).

Riessman (2006) supports the use of narrative, by acknowledging the diverse and different methodological ways of creating meaning and making sense of the world, and states:

Science cannot be spoken in a singular, universal voice. Any methodological standpoint is, by definition, partial incomplete, and historically contingent. Diversity of representation is needed. Narrative analysis is one approach, not a panacea; it is suitable for some situations and not others” (Riessman, 2002, p. 206).
This section describes how narrative epistemological assumptions challenge four major empirical assumptions associated with rigour within the research context: reliability, objectivity, generalisability and validity. Pinnegar & Daynes (2006) contend that Michelagnoli, Pritchard & Phillips (2003) narrative inquiry cannot accommodate these assumptions as the research is based on connectedness rather than reliability, relatedness to the research participant in contrast to objectivity, a focus on the particular rather than generalisability to other settings and, finally, the desire for understanding the particular rather than attempting to predict or control the world. This research study favours the assumptions associated with narrative inquiry. The study focuses on connectedness and relatedness as I and the family members seek to develop an understanding of the experience of an AYA family member living and dying of cancer. This study is focused on that particular story and cannot be generalised to other settings. The validity of the study will be related to the trustworthiness of the study.

**Research Process**

**Ethical Approval Processes**

Full ethical approval was obtained before the commencement of this study (Approval number ECN – 05 – 146, see Appendix B).

The initial research proposal included family members aged 12 years and over. It was believed that those siblings of an AYA who had died of cancer had little opportunity to tell their story. Therefore, ethics approval was obtained to include young people aged 12 to 18 in the study. For the purpose of this study it was assumed that the young people in this research would fit the definition provided by the National Health and Medical Research Council (NHMRC 1999, p. 66) as “subject to the law in the relevant jurisdiction a minor, who may have the maturity to make decisions whether or not to participate in research.” This was argued in relation to Piaget’s developmental theory that suggests a young person aged 12 and above is in the formal operational stage of development and has the cognitive ability and maturity to make competent decisions about research (as cited in Crisp & Taylor, 2005). Moreover, the research design ensured the young person had the maturity to participate in the research by checking that they understood the research study and what was required of them. In addition, the Southern Cross University’s Centre for Children and Young People Code of Ethical Practice (Fitzgerald & Graham, 2004), the UN Convention on the Rights of the Child
(CROC) (United Nations Assembly, 1989) and the National Statement on Ethical Conduct Involving Humans (National Health and Medical Research Council (NHMRC), 1999) all support the value of young peoples’ participation in research, if the research increases the knowledge of issues for young people and has the capacity to influence policy and practice. It was thought that the stories told by young people in this study would inform the care provided to young people and their families living with and dying of cancer. However, once the process of recruitment commenced, no family members under the age of 18 volunteered to tell their story. Therefore, the ethical issues associated with young people having the maturity to make a decision to participate in research was no longer relevant to this research study.

The potential emotional and psychological risk for the family members in this study, related to the sensitive nature of the research and the grief and pain that would probably resurface through telling the story of an AYA family member who had died of cancer. Other risks concerned my own experience as a mother, who had lost her adolescent son to cancer and the possible blurring of boundaries during the interview and the risk of over identification and over involvement in the family members’ stories.

The risks were minimised in many ways. The family members all self selected to be in the study and the associated risks were explained to the family members verbally and in the information sheet (see Appendix G). To be included in the research the AYA’s death was required to be 12 or more months previously. Whilst there is no arbitrary amount of time to determine if an interview may intensify, interrupt and harm the normal grieving process, it was thought that 12 months would have given the family members time to have created some meaning out of the death and be aware if they were experiencing a complicated grief reaction. There is the assumption that asking people who are grieving about how they are feeling causes additional pain. Dr Jennifer Buckle contends that not asking people about their experience results in further loss. There is a sense of isolation because no one is talking about their loved one (IPP-SHR podcast, 2010). It has also been demonstrated that talking about this painful experience can create some healing in the grieving process (IPP-SHR podcast, 2010; Grinyer, 2004a). For example, Grinyer (2004a) conducted a follow up study of parents who had provided a narrative account of the experience of caring for a young person with cancer, the majority of whom had died, in order to understand the long-term effects of the research participation. In this study, the family members acknowledged the emotional demands
of recalling painful memories, but overall they believed they had benefitted from the research. The parents stated they valued their involvement and identified the following as positive outcomes: the opportunity to tell their story was seen as therapeutic; the feeling of isolation had been reduced; the outcome of the research was significant; and they interpreted the resulting publications as a lasting memorial to their son or daughter.

In relation to my role as a researcher, I am an experienced counsellor with over 25 years working in the mental health field; I am aware of a complicated grief reaction, which may require some professional intervention and a normal painful grief response, which can be healing and cathartic. I provided a list of professional Counsellors, who were willing to provide their services if it became evident that a family member required professional help. In addition, one to two weeks after the completion of each interview I phoned the family member to ask how they were feeling. I also maintained contact, asking for feedback on the transcripts and the analysis through regular email. None of the family members required professional intervention and most valued the opportunity to tell the story from start to finish, which they had not had the opportunity to do before.

The family members were aware of my story due to an article in the magazine Take 5 (Parrish, 2007) (see Appendix E) which could have created the possibility of blurred boundaries between myself and the family members. As mentioned earlier, my mental health experience and knowledge enabled me to ensure that the interview was conducted with the emphasis on the family members telling their story and my story was never part of the interview process. It also became apparent once the interviews started, that the family members’ main objective was to tell their own story and I was ‘a sounding board’ to facilitate the telling of the stories. Each of the family members had self-selected to tell their stories. Most said it made it easier to tell the story to someone who really knew. This is reinforced in the use of narrative as the methodology. Bruner (1987) has suggested tellers and listeners must share some deep structures, in order for the listener to fully grasp what the other is saying.

The research study was also seen to be of some risk to myself having lost my own son, and listening to similar stories of pain and loss, my own pain may have resurfaced and I could have become emotionally vulnerable. I was aware of this before starting the study and with my mental health background I have developed a degree of self awareness and was prepared for the emotional impact the stories would have on me as a mother.
Therefore, I conducted the interviews over an 18 month period which gave me the opportunity to reflect on the stories and not become overwhelmed with too many stories of suffering at the one time. This created healing time for me, and the opportunity to reflect and create meaning from the stories of pain and loss. I also debriefed with my husband and my supervisor about the stories. As the study progressed it was obvious that my own story of loss and pain was separate from the stories of loss and pain of the family members. The emotion I felt when interviewing the family members and becoming involved in the transcripts, was more of an in-depth empathic understanding of what they had and were experiencing. In some respect, listening to the stories enabled a reduction in the feeling of isolation as my story could be understood within the context of other similar stories. I had the contact number of Counsellors if I thought the stories were overwhelming me, and I did not require their services.

One of the ethical issues associated with qualitative research is confidentiality. The original ethics proposal stated that pseudonyms would be used to protect the family members’ identities and that real names would only be used with the family members’ permission. The further I went into the research study and the more interviews I conducted, it became obvious to me that the family members were telling their stories in order for their AYA to be honoured and remembered. I realised family members felt that the use of a pseudonym would prevent the family member identifying with the story of their loved one and could betray the loved one’s memory.

This is supported by Anne Grinyer (2002b) who believed the central importance of de-identified information, when conducting ethical research, is based on the premise that participants actively desire anonymity. She discovered, in her research of a similar nature to this study, that this premise is more complex than previously perceived. The parents in her research, who had lost an AYA to cancer, had shared some of the family’s most intensely painful and intimate details. She pondered the effect of seeing their lost son or daughter being referred to by a pseudonym. She also raised the ethical dimension of the researcher deciding on behalf of the participants, without consultation, that their identity should be concealed. When she asked if they would prefer to be allocated a pseudonym or real name, the majority said they would prefer to use real names. Grinyer (2002b) concluded that the issue of protecting people from harm, by hiding their identity, needs to be balanced with the participant’s feeling a loss of ownership of the
story. She therefore suggested showing the participants their words in print at a draft stage, so they could make an informed decision about protecting their identity.

As such, I submitted a change of protocol to the Ethics Committee, in order for real names to be used in this study. This was approved and the study was given a new approval number (ECN – 08 – 029 see Appendix C). Consequently, all family members were given a copy of the transcript and asked if they would prefer to use pseudonyms or real names. All family members requested to use real names. Due to the fact that there were two AYA’s called Brenton, two called Mathew/ Matthew, two called Paul and another was named Anthony (my son’s name), second names were used in order to identify these AYAs.

**Recruiting Family Members**

The family members in this study were a purposeful sample who have experienced the death of an AYA to cancer. Purposive sampling involves the deliberate selection of specific individuals, events or settings because of the crucial information they can provide. Therefore, purposeful sampling selects information rich cases for in-depth study (Taylor, Kermode, & Roberts, 2006). In this study family members were selected who had an AYA family member die of cancer.

The inclusion criteria for the family members in this study included, parents, siblings and grandparents, aged 12 to 65, who had lost an AYA to cancer, aged 16 to 25 years, over 12 months ago and were willing to tell their story about the experience. Given the nature of the research process with an emphasis on the interview and open-ended questions, the only exclusion criterion for this group of people was communication difficulties with the English language. Initially, the family members were to be recruited through an organisation supporting young people living with cancer, but unfortunately this did not eventuate. I managed to conduct four family interviews of people associated with this organisation, through the friendships my two other children had developed with members of this organisation during Anthony’s cancer and the aftermath following his death. Due to the isolation we as a family experienced during Anthony’s cancer treatment and dying, I was only aware of one other family member with an adolescent who had eventually died of cancer, although her daughter did not fit the inclusion criteria for this study as she was aged 12 when she died. This mother was keen to tell her story of her experiences in the health system, particularly the isolation
she felt within the adult palliative care system, so it was decided to include her in the study.

Due to problems associated with recruitment of family members it was decided to approach the media section of Southern Cross University, and an article was published in two local newspapers (see Appendix D) and I was interviewed by two local radio stations and one local television news station in October 2006. This provided some interest from people within the local geographical area, but unfortunately only three of these people fitted the inclusion criteria for participation in this research. Eventually, I was approached by a freelance reporter from an Australian magazine “Take 5” who had read the story in the local newspaper. As a consequence, my son’s story and information about my research was published in this magazine with my contact details in January 2007 (see Appendix E). From this article I received many emails and phone calls, some expressing sympathy, some wanting to share their story of their children living with cancer, some sharing their stories of their children or AYA who had the same rare cancer as Anthony, and others who had had an AYA family member die of cancer. The majority of the people who had had a family AYA die of cancer, expressed a wish to participate in the study. All these people were contacted by phone and email and the study’s aims, objectives and the interview process was explained to them. This provided the opportunity for these potential family members to find out more about the study and my place as a researcher in the process. This resulted in 19 people from various parts of Australia being recruited to the study. The family members were aware of Anthony’s story through the “Take 5” article and they expressed relief that they would be able to tell their story to some-one who knew and understood.

The final number of family members, recruited to the study, who wished to tell the story of their experience of living with an AYA who lived and died with cancer, was 26. Fourteen of these family members were mothers, one was a stepmother, three were fathers, six were siblings, one was a grandmother and one was a grandfather. Of these 26 family members 16 individual interviews were conducted, four family members were interviewed as couples, three were interviewed as a couple and sibling, and the remaining three were interviewed as mother and sibling, with the mother being interviewed twice in separate interviews with two different children. In total, there were 22 interviews. The length of time since the AYA’s death varied from 20 years to 12
months. The age range of the AYA’s was 12 years to 21 years. Table 4.1 summarises this information and identifies the type of interview.

<table>
<thead>
<tr>
<th>Family member’s relationship</th>
<th>AYA information</th>
<th>Type of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alan, Father of Naomi</td>
<td>Naomi, died of leukaemia in May 2001 aged 19</td>
<td>Face to face interview with wife Marilyn and daughter Rebekah</td>
</tr>
<tr>
<td>Andrea, Stepmother of Grant</td>
<td>Grant died of rhabdomyosarcoma in March 2004 aged 20</td>
<td>Face to face interview partner of Shane</td>
</tr>
<tr>
<td>Arleen, Mother of Mathew James</td>
<td>Mathew James died of leukaemia in May 1996 aged 22</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Cameron, Brother of Kristie</td>
<td>Brother of Kristie, who died of rhabdomyosarcoma November 2000 aged 17</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Cathie, Sister of Paul Vincent</td>
<td>Paul Vincent, died of leukaemia in February 1981 aged 16</td>
<td>Face to face interview with mother Heather, sister of Trish</td>
</tr>
<tr>
<td>Cheryl, Mother of Paul Malcolm</td>
<td>Paul Malcolm died of glioblastoma in December 1998 aged 18</td>
<td>Individual telephone interview</td>
</tr>
<tr>
<td>Deborah, Mother of Matthew Anthony</td>
<td>Matthew Anthony died of alveolar soft part sarcoma in September 2003 aged 18</td>
<td>Individual telephone interview</td>
</tr>
<tr>
<td>Denise, Mother of Brenton James</td>
<td>Brenton James died of melanoma in August 2005 aged 16</td>
<td>Individual telephone interview</td>
</tr>
<tr>
<td>Fulvia, Mother of Jayde</td>
<td>Jadye died of rhabdomyosarcoma in December 2006 aged 17</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Geoff, Father of Michael</td>
<td>Michael (Mick) died of acute lymphoid leukaemia (ALL) in July 2005 aged 21</td>
<td>Individual face to face interview husband of Helen</td>
</tr>
<tr>
<td>Heather, Mother of Paul Vincent</td>
<td>Paul Vincent died of leukaemia in February 1981 aged 16</td>
<td>1st interview face to face with daughter Cathie, 2nd interview face to face with daughter Trish</td>
</tr>
<tr>
<td>Helen, Mother of Michael</td>
<td>Michael (Mick) who died of acute lymphoid leukaemia (ALL) in July 2005 aged 21</td>
<td>Individual face to face interview, wife of Geoff</td>
</tr>
<tr>
<td>Irene, Grandmother of Thomas</td>
<td>Thomas died of osteosarcoma in December 2001 aged 16</td>
<td>Individual telephone interview, wife of Mike</td>
</tr>
<tr>
<td>Jenny, Mother and Geoff father of Brenton Duncan</td>
<td>Brenton Duncan, who died of a rare sarcoma in October 2001 aged 16</td>
<td>Individual telephone interview</td>
</tr>
<tr>
<td>Family member’s relationship</td>
<td>AYA information</td>
<td>Type of interview</td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Jo, Mother of Christopher</td>
<td>Christopher died of leukaemia in March 1995 aged 16</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Kerry, Mother of Alinta</td>
<td>Alinta died of glioblastoma in September 2001 aged 12</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Lauren, Sister of Grant</td>
<td>Grant died of rhabdomyosarcoma in March 2004 aged 20</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Marilyn, Mother of Naomi</td>
<td>Naomi died of leukaemia in May 2001 aged 19</td>
<td>Face to face interview with husband Alan and daughter Rebekah</td>
</tr>
<tr>
<td>Mike, Grandfather of Thomas</td>
<td>Thomas died of osteosarcoma in December 2005 aged 16</td>
<td>Individual face interview, husband of Irene</td>
</tr>
<tr>
<td>Pam, Mother of Tamina</td>
<td>Tamina died of Ewings sarcoma in April 1999 aged 22</td>
<td>Individual face to face interview</td>
</tr>
<tr>
<td>Rebekah, Sister of Naomi</td>
<td>Naomi died of leukaemia in May 2001 aged 19</td>
<td>Face to face interview with father Alan and mother Marilyn</td>
</tr>
<tr>
<td>Shane, Father of Grant</td>
<td>Grant died of rhabdomyosarcoma in March 2004, aged 20</td>
<td>Face to face interview with partner Andrea</td>
</tr>
<tr>
<td>Sue, Mother of Ben</td>
<td>Ben died of melanoma in May 2006, aged 18</td>
<td>Individual face to face interview</td>
</tr>
</tbody>
</table>
| Tania, Sister of Anthony Charles and Susie | Anthony Charles died of leukaemia in June 1989 aged 15  
Susie died of leukaemia in April 2001 aged 23 | Individual phone interview, daughter of Val |
| Trish, Sister of Paul Vincent| Paul Vincent died of leukaemia in February 1981 aged 16 | Face to face interview with mother Heather |
| Val, Mother of Anthony Charles and Susie | Anthony Charles died of leukaemia in June 1989 aged 15  
Susie died of leukaemia in April 2001 aged 23 | Individual phone interview, mother of Tania |
The number of family members and interviews in this study is congruent with the assumptions of qualitative research, which “emphasises the central role of the research context and people in generating knowledge that is personal and practical, and which comes from the perspective of people engaged actively in their lives” (Taylor, 2006b, p. 399). The emphasis is not on the number of family members, but more on the quality and depth of information elicited (Wilson, 2007). As such, this study did not seek high numbers to generalise results or use them for predicative purposes, rather it sought to provide rich in-depth accounts of the family members’ experience.

All the potential family members were contacted by phone to determine their interest in the study. All expressed a desire to be part of the study. A covering letter (see Appendix F) the information sheet (see Appendix G) and consent form (see Appendix H) were mailed to them with a stamped return address envelope, with a request that the consent form be returned. Once the consent form had been returned and signed, family members were contacted by phone and email to determine the where, when and how the interview would take place. All but one of the face-to-face interviews was conducted in the family member’s home, which provided for the family member to be able to tell their own story in their own environment. The one face-to-face interview that was not conducted in the person’s home was at the request of the family member who stated she felt more comfortable outside of her family home.

The next section provides an overview of the intricacy of narrative analysis and issues related to how to develop a framework for the analysis and interpretation of the stories.

**Narrative Analysis**

In concert with the diverse understanding of the meaning of narrative as a methodological approach, discussed in chapter three, narrative analysis does not have a defined method or approach and a systematic form of analysis is often lacking. Narrative analysis has been criticised for being more of an art than research (Lieblich, et al., 1998). The method often appears to be based on intuition (Elliot, 2005; Redwood, 1999; Riessman, 1993), talent, or clinical experience (Lieblich, et al., 1998). Narrative analysis has been described as being unclear about its epistemological influences, because it draws on philosophy, anthropology, sociology, psychology, sociolinguistics, ethnomethodology and literary criticisms (Priest, Roberts, & Woods, 2002). However,
the earlier discussion in Chapter Three of the historical roots of narrative has provided insights into the epistemological underpinning of narrative inquiry and analysis. While this is so, a review of the literature by Lieblich-Mashiach, and Ziblier (1998) found no comprehensive models describing existing methods of analysing or reading narratives. They contended that the classification of methods is relatively rare.

Emden (1998b) argues for the development of a narrative tradition in nursing inquiry, with continued sharing of ways in which narrative inquiry can be conducted. Different theorists provide various forms of analysis and highlight different issues and dilemmas. Riessman (2004b) believes boundaries are fuzzy between models that can be combined. Ohlen and Bergbom (2000) suggest narratives belong to the life world, where the researcher creates a caring relationship with the narrator, which may have a healing dimension. They suggest analysis and interpretation may vary although the interpretation is required to be grounded in the narrator’s lived experience. “The life world constitutes the basis for both the narrative and the interpretation” (Ohlen & Bergbom, 2000, p. 701). “Provided narrative researchers remain faithful to their interest in the potential of stories the range of possible influences and strategies is vast. The spirit of narrative inquiry is perhaps best nurtured by a mature appreciation of multiplicity and difference” (Emden, 1998b).

Even though narrative analysis appears to have no clear method or defined approach to the analysis of a story, Elliott (2005) asserts that the researcher is nevertheless required to produce convincing interpretations of stories. The interpretation requires some heuristic devices or procedures as means of exploring the possible interpretations of the stories, which enable the researcher to interpret the narrative beyond the obvious content.

**NARRATIVE MODELS OF ANALYSIS**

In order to provide some understanding of the heuristic devices that assist in the interpretation of stories, Mishler’s (1995) narrative typology demonstrates the diversity of narrative analysis. From reviewing this diversity in the typology, the following authors and forms of narrative analysis were identified as providing some guidance to analysis of the sensitive stories in this study by providing a true representation of the stories told. Table 4.2 illustrated these forms of analysis and their authors
Table 4.2  Forms of Narrative Analysis

| Interview as narrative | Mishler (1986)  
| Riessman (1993) |
| Guidelines for conducting narrative analysis | Riessman (1993)  
| Reading analysing and interpreting narrative | Lieblich, Tulval & Zibler (1998) |
| Narrative configuration | Polkinghorne (1995)  
| Emden (1998) |
| Illness narratives | Kleinmann (1988)  
| Frank (1997)  

The Interview as Narrative: Mishler and Riessman

The use of the open-ended interview was introduced into narrative inquiry by Mishler (1986,a,b) who questioned the traditional interview method, proposing that the standardisation of interview questions and responses neglects the issues of language, meaning and context. Within the context of narrative inquiry and the emphasis on stories as topics of investigation, traditional interviewing practices are challenged. He considered traditional interviewing practices suppress the stories or limit answers to specific questions.

For example, Paget (1983) describes how similarities between her own and the respondents’ stories influenced the questions she asked and her understanding and interpretation of the story. In addition, her hesitant and searching way of asking questions encouraged searching, reflective and extended responses. Mishler (1986b) describes the interview context as the interviewer and the interviewee “engaged together in the same task of trying to understand important life experiences” (p. 245). These interviewing practices produce in-depth narrative accounts (Mishler, 1986a, 1986b).

Atkinson (1997) agrees, believing the emphasis of the interview should be on empowerment and provide the opportunity for insight into the storyteller’s problems,
experiences and interests. This has the potential to take on a therapeutic and emancipatory aspect.

Within this context the open-ended interview is an appropriate method to create a story or narrative of historical events. Riessman (1993) and Mishler (1986) both stress the importance of language within the context of the open-ended interview. Riessman (1993) quotes Burke (1950), who states “language is not merely descriptive … not just trying to tell people how things are … it is trying to move people” (p. 21). Central to this is the understanding that stories are not just descriptive events but are told to create meaning and connect the listener to the emotional components of the story.

Mishler’s (1995, 1986b) form of narrative analysis requires a consideration of the context of the interview as different contexts can result in different stories. Therefore, consideration needs to be given to the situation and process of the interview and attention to interviewer and the family member’s interaction to capture the language and emotional components of the story. In other words the researcher’s interpretation and analysis cannot be distanced from the phenomena under study and its context.

Riessman (1993) and Mishler’s (1986a,b) emphasis on the open-ended interview as a form of telling the story provides guidance for this study. It requires me to provide an opportunity for the story to be told with an emphasis on context and meaning. The model also emphasises the importance of me and the family members jointly engaged in constructing the interview and the emancipatory function of the interview. The sensitive nature of my study lends itself to the open-ended interview as described in this section. This form of interviewing creates the environment for the family members to freely tell their story.

**Guidelines for Conducting a Narrative Analysis: Riessmann**

Riessman (1993) advocated the analysis of the narrative as a whole to understand how meaning is created for the storyteller. This meaning is created in the way the story is told and the language used. The way the story is told and the language used is dependent on various narrative genres. The genres of interest in this research relate to narratives of the experiences of disruption and upheaval. This genre is emphasised in the illnesses narrative that will be referred to in more detail later in this chapter.
Riessman (1993) discusses five levels of representation within narrative inquiry, these being: attending, telling, transcribing, analysing and reading, with porous boundaries between them. Embedded in these representations is the task to distinguish narrative and non-narrative parts of an interview or defining the boundaries of the narrative (1986a).

Following on from this, Riessman (1993) has provided guidelines for conducting narrative inquiry that are helpful in determining the boundaries of the narrative and other questions related to her representation of narrative inquiry. These representations include how talk is transformed to text, who determines what the narrative means and are alternative readings possible. The guidelines identify the following components for conducting narrative analysis: telling, transcribing and analysing.

Riessman’s (1993) guidelines for conducting a narrative analysis provide a structure for the analysis and interpretation for the stories in this study. In addition to focusing on the boundaries of the narrative, it is important to ensure the aims and objectives of this study are accomplished.

Reading, Analysing and Interpreting Narrative: Lieblich Tulval-Mashiach and Zibler

Lieblich Tulval-Mashiach and Zibler (1998) developed a model for the classification and organisation of types of narrative analysis. They discovered two independent dimensions exist for reading, interpreting, and analysing life stories: (i) holistic versus categorical and, (ii) content versus form.

A combination of these two dimensions provides four cells and four ways of reading narrative: (i) holistic content, (ii) holistic form, (iii) categorical content and (iv) categorical form (see Table 4.3)

Table 4.3 Framework for Narrative Analysis

<table>
<thead>
<tr>
<th>Holistic Content</th>
<th>Holistic Form</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>What</em> happens in a story, appreciated as an overall pattern</td>
<td><em>How</em> the pattern of the story unfolds taken in context</td>
</tr>
<tr>
<td>Categorical Content</td>
<td>Categorical Form</td>
</tr>
<tr>
<td><em>What</em> happens in a particular episode of a story, analysed for structure</td>
<td><em>How</em> a particular episode of a story occurs</td>
</tr>
</tbody>
</table>

(Bleakley, 2005, p. 537)
Lieblich et al (1998) claim their model provides a framework for ordering a growing number of methods and ideas for reading a life story. A combination of the two dimensions is helpful in guiding the analysis of my study, but in particular the holistic form and the categorical content cells.

The holistic form focuses on the narrative as a whole and the unit of analysis is the structural element of the narrative. The development of the plot relates to Gergen and Gergen’s (1986) prototypical narrative forms, the progressive narrative, the regressive narrative and the stable narrative.

These general narrative patterns can be combined, to construct more complex plots (Tulval-Mashiach, 2006). For the purpose of my study the categorical content form of analysis provides a frame for organising the story that has emerged as a result of the holistic form of analysis, into themes or categories. This organisation of the family member’s stories into themes or categories enables the researcher to construct a narrative that identifies commonalities and themes within and between the family members’ holistic form stories, establishing, common elements in the experience of family members.

**Narrative Configuration: Polkinghorne and Emden**

Polkinghorne (1995) developed the concept of narrative inquiry further by dividing narrative inquiry into distinct types, these being narrative analysis and paradigmatic analysis of narratives. The distinction of the types is based on Bruner’s (1986) distinction of two modes of thought: paradigmatic cognition and narrative cognition.

In paradigmatic analysis of narrative, the analysis is of stories for common elements and in narrative analysis, the analysis from elements to stories (Polkinghorne, 1995). In other words, “in analysis of narratives” the narratives are the source of knowledge, (whereas) the narrative in “narrative analysis” is the result of the research (Smeyers & Verhesschen, 2001, p. 76). Polkinghorne’s model therefore provides some assistance in plotting the stories to create the narratives for this research.

Bruner’s (1986) narrative cognition mode of thought is applied using the narrative configuration model for narrative analysis (Polkinghorne, 1995). According to (Polkinghorne, 1995, p. 11) “narrative cognition configures the diverse elements of a
particular action into a unified whole, in which each element is connected to the central purpose of the action”.

Polkinghorne’s (1995) narrative analysis or narrative configuration is similar to Lieblich et al (1998) concept of holistic form. Within Polkinghorne’s (1995) concept of narrative as story or narrative analysis, the story is organised as a whole by the means of a plot in which the contextual meaning of individual events can be displayed (Polkinghorne, 1995).

The plot creates the temporal boundaries of the story and the selection of happenings to be included in the story (Polkinghorne, 1995). The meaning created by stories relies on the assumption that time moves from the past, to present, to future and that events, motives, and interpretations can affect human actions. These affects are only known retrospectively, the plot synthesises these retrospective actions and outcomes into a storied form (Polkinghorne, 1995). Polkinghorne (1995) calls this process of developing the plot of a narrative, narrative configuration.

Narrative configuration is defined as:

[t]he process by which happenings are drawn together and integrated into a temporally organised whole. The configuration process employs a thematic thread to lay out happenings as part of an unfolding movement that cumulates in an outcome. The thematic thread is called the plot, and the plot’s integrating operation is called emplotment. When happenings are configured or emplotted, they take on narrative meaning. That is, they are understood from the perspective of their contribution and influence on a specific outcome (p. 5).

Therefore, it provides a storied description of a person’s journey through a life episode. This process of narrative configuration or narrative emplotment as a form of analysis, provides guidance on how to integrate the events and happenings into a coherent plot concluding with the outcome or story from the experience. By plotting the stories of family members’ experiences an understanding is developed of some of the events, motives and interpretation of their experiences. Through the process of emplotment, transitional or turning points, as described by Lieblich et al (1998), can be identified.

In contrast Bruner (1986) described paradigmatic cognition as the “logico-scientific” mode of thought, which attempts to fulfill the ideal of a formal, mathematical
description and explanation. It employs categorisation or conceptualisation by classifying a particular instance as belonging to a category or concept. In Polkinghorne’s paradigmatic analysis of narratives, the data are narratives and stories, which are analysed using paradigmatic analytical procedures to produce categories out of common elements within the narratives and stories (Polkinghorne, 1995). The researcher looks for common themes that experiences have in common, or typologies or genres of stories, characters or settings (Polkinghorne, 1995; Smeyers & Verhesschen, 2001).

Polkinghorne’s (1995) concept of paradigmatic analysis is similar to Lieblich et al’s (1998) categorical content concept of an analysis of narrative. The development of themes or commonalities within the stories of the family members I assumed as being relevant for this study. Whilst the stories on their own provide a narrative of the individuals’ experience, through categorical content and paradigmatic analysis the meta-narrative of the family members experience can also be told. This provides some understanding of the common experience for the family members who are part of this study.

Emden (1998a) found that Polkinghorne’s (1988) human science perspective provided minimal guidance on how to create a core story or narrative. Therefore, Emden devised guidelines for the development of the core story. These guidelines are discussed in more detail when discussing how the various models were applied to interpret the stories in this study.

In summary the model of narrative configuration provides assistance for this study. Polkinghorne’s (1988, 1995) two methods of narrative inquiry, paradigmatic analysis and narrative analysis, present similarities to Lieblich, Tulval and Ziblier’s (1998) holistic form and categorical content types of analysis. The elements of both models provide direction on how to create a narrative and uncover the themes or categories of the narrative. Emden (1998b) has demonstrated that there is no pure form of narrative analysis and has developed her own guidelines for narrative analysis to emplot or configure the narrative which will be discussed later in this chapter.
The Illness Narratives - Understanding the Context of Suffering: Kliemman, Sakalys and Frank

The stories in this research study cannot be separated from the stories of suffering that are intrinsic to the theoretical perspectives of the illness narratives. The illness narratives extend narrative analysis by providing a reference to understand stories of suffering and how people attempt to make sense of these stories.

The different functions of the illness narratives are described “to construct an illness experience, to reconstruct life history, to make disease and illness understandable, and to collectivise the illness experience” (Hyden, 1997, p. 64). Hyden (1997) reviewed ten years of research on the illness narratives. Although this work is now dated, it can still provide useful insight into the development of the illness narratives. Since the illness narrative first began to appear in the early 1980s, the concept has changed thematically, theoretically and methodologically. Thematically, illness narratives now concentrate on the experience of the patient’s suffering and not the clinical practice and experience of doctors. Providing a narrative of one’s life with a chronic illness provides a framework for the narrator to give meaning for the events that have disrupted the life course (Hyden, 1997). Theoretically, illness narratives now play a central role in understanding the illness experience with a greater emphasis on suffering as illness. Thus, the illness patients experience is a social reality open to study, which is distinct from the biomedical illness definition (Hyden, 1997).

Whilst the illness narratives focus on illness, they can also inform this study. The narratives of family members in this study have been disrupted by the diagnosis, treatment and finally death of a young family member from cancer. The stories from these experiences are stories of suffering. As a result new perceptions of one’s relationship with the world are required (Sakalys, 2003). The illness narratives provide the context to answer such questions as “How do persons organise … lived experience?”, “What do persons do with this experience to give it meaning and to make sense out of their lives?” and “How is lived experience given expression?” (White & Epston, 1990, p. 9). Therefore, the illness narratives are essential in informing the interpretation of the stories in this study.
In order to develop my understanding of the illness narratives in more detail the work of three major authors in the area of illness narratives will be discussed. The major authors are Kliemman (1988), Sakalys (2000, 2003) and Frank (1997).

Klienman and the Wounded Healer

The importance of the illness narratives was first introduced by Klienman (1988) through clinical and ethnographic studies of patients with chronic illness. He conducted these studies in order to understand what the illness experience was like for the patient. He discovered that patients order their experience of illness - what it means to them and to significant others - as personal narratives. These illness narratives “edify us about how life problems are created controlled and made meaningful” (Kleinman, 1988, p. xiii). The illness narrative is about suffering, the person’s previous perspective of the world has changed and the person is in a transitional situation in which they must create some meaning of the experience (Gergen & Gergen, 1986; Kleinman, 1988).

The illness narrative is “a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering” (Kleinman, 1988, p. 49). “Through narrative, experience and meaning are rendered whole” (Atkinson, 1997, p. 331). The meaning of the symptoms, the cultural significance of the illness, the personal and social meaning of the illness experience and the clinician’s or researcher’s interpretation of the illness experience determine the illness narrative of the person (Kleinman, 1988).

Therefore, illness narratives develop narrative inquiry into the area of medical care and illness where previously inarticulate themes of illness and suffering are given voice (Fins, et al., 2000). These illness narratives can help the patient, the family and the practitioner to, at times, make a significant difference (Kleinman, 1988). The interpreter of the illness narratives can uncover patients’ concerns and may develop an understanding of the experience of suffering (Atkinson, 1997). Kleinman (1988) advocates the medical interview as a means of understanding the illness narrative through the “empathic witnessing of the existential experience of the suffering” (Kleinman, 1988, p. 10).

Kleinman’s (1998) emphasis is on the wounded healer, to strengthen the understanding and empathic bond of a clinician with the patient. He has provided an understanding and a methodology of giving voice to the stories of suffering from the patient’s perspective.
He explains that his “methodology is a framework for assuring that the uniqueness of the illness as human experience in all its many social and personal manifestations, become the center of the healer’s gaze” (Kleinman, 1988, p. 228). It is therefore a methodology to assist the clinician in understanding the illness from the patient’s perspective.

Sakalys and the Narrative Therapeutic

Kliemann’s (1988) concept of the illness narratives is supported by Sakalys (2000) who contends that illness narratives illuminate ideological differences between the biophysical understanding of the illness and the patient’s experience of the illness. As such, they have the potential to challenge the dominant health care ideologies and can be a form of cultural criticism (Sakalys, 2000). The author advocates for relational restructuring, in which the patient and the nurse co-construct a joint narrative, weaving the medical meta-narrative with the patient’s own illness narrative, recognising that no single narrative has a claim to authenticity.

Sakalys (2003) further develops the importance of the illness narratives stating, “narrative increases self awareness by enabling reflection and formulation of experience” (Sakalys, 2003, p. 231) and “narratives attach persons to others” (Sakalys, 2003, p. 232). Sakalys’s (2003) approach to illness narratives is based on the need for people to integrate the experience of life threatening illness into the continuity of life. Sakalys (2003) promotes the use of narrative within nursing practice as a caring/healing modality that can restore personhood, coherence, and connectedness. This can be achieved through the process of what Sakalys refers to as narrative therapeutics, in that understanding of the patient’s subjective experience of illness requires some understanding of their narrative. This understanding “requires engagement and deliberate action based on the skills of understanding, recognising, and eliciting narrative” (Sakalys, 2003, p. 234). This requires the ability to listen for the patient’s meaning and provide the patient with the opportunity to be heard (Sakalys, 2003). This use of therapeutic narrative may facilitate healing by “giving them language, to bring fragmented illness experiences together, to discover patterns in experience, to construct explanation and meaning, and to facilitate a sense of connection between self and others” (Sakalys, 2003, p. 239).
Klienman (1988) and Sakalys (2000, 2003) whilst providing some guidance on understanding the transitional experiences of suffering within the context of the illness narratives, it is more to develop the clinician’s understanding of the illness from the patient perspective and to provide empathic patient care. This relationship is developed within the culture of the clinical encounter. The illness narratives in this study are separate from the clinical encounter and are specific to the experience of the family members and their journey of suffering. Thus the metaphor of the wounded healer does not provide the context for the stories of suffering to be understood from the storyteller’s perspective. Frank (1995) introduces the concept of the wounded storyteller to explain this.

Frank and the Wounded Storyteller

Frank (1995) extends the illness narratives from the metaphor of the wounded healer and introduces the metaphor of the wounded storyteller. He equates illness to a “narrative wreck” due to the loss of a sense of temporality – a past that leads into the present and sets the place for the foreseeable future. This creates a disrupted memory with no coherent sequence of the whole. Similar to Gergen and Gergen’s (1986) concept of dramatic engagement, illness dislocates the relation to the whole as “the present is not what the past was supposed to lead to, and what ever future will follow this present is contingent” (Frank, 1997, p. 60). He postulates the way out of the narrative wreck is the telling of stories, specifically self-stories. Frank (1997) claims that the telling of stories serves to connect the past with the present and memory is restored as coherent.

Telling the story transforms the experience from a disease that sets the body apart from others, into a common bond of suffering, a bond that joins the wounded in their shared vulnerability. He asserts stories of “the wounded healer and the wounded storyteller are not separate, but are different aspects of the same figure” (Frank, 1997, p. xii). This is true in this study with family members and the researcher having a shared vulnerability due to suffering that is informed by the loss of an AYA to cancer. As mentioned earlier, stories must mesh with other stories that when told, and heard, share deep structures – and contextual understanding (Bruner 1987). This understanding of the family members’ stories of suffering through the researcher’s story of suffering would
influence how the family member constructed their story, because of our shared understanding which is not accessible to those who have not shared a similar story.

Frank (1997) extends the power of stories of suffering believing that wounded storytelling is an ethical act. “In stories, the teller not only recovers her (sic) voice; she (sic) becomes a witness to the conditions that rob others of their voices. When any person recovers his (sic) voice many people begin to speak through that story” (Frank, 1997, p. xiii). Therefore the storyteller creates a testimony of the experience of suffering and engages in moral action, because as the storyteller attempts to change his or her own life they affect the life of others (Frank, 1997). This giving voice to the family members provides the opportunity to articulate what has previously not been articulated. The stories will provide a voice for others suffering a similar experience to hopefully speak through the stories.

These stories are told through various narrative genres and typologies. Frank (1997) proposes three narrative types: the restitution, the chaos and the quest. He emphasises that in any illness narrative all three types are told, each interrupting the other. Each of the narratives reflects cultural and personal preferences, which can create barriers in listening to the ill, as the stories are guided towards these cultural and personal narrative preferences (Frank, 1997). All three narratives were seen as relevant to this study. They will be discussed in more detail in order to provide some understanding of how they influenced the interpretation of the stories in this study.

The restitution narrative: Illness in the imaginary

The plot of the restitution narrative has the basic storyline of becoming well again. “The storyline is filled with talk of tests and their interpretation, treatment and their possible outcomes, the competence of physicians, and alternative treatments” (Frank, 1997, p. 77). In the restitution narrative, the memory is not disrupted, and the coherent sequence of past, present and future is only interrupted until restitution (Frank, 1997). Restitution narratives “depend on a mechanist view of the body and a model of illness as a temporary breakdown that can be repaired” (Atkinson, 1997, p. 337). Restitution narrative are stories “told by a self but not about a self” (Frank, 1997, p. 92). They are stories that “bear witness, not to the struggles of the self, but to the expertise of others”
(Frank, 1997, p. 92). “The ill person can only be a hero in such narratives by virtue of the superior heroism of the medical practitioner” (Atkinson, 1997, p. 337).

The restitution story is the culturally preferred narrative, although fixation on the restitution narrative can exclude other stories. Stories that can be excluded concern our mortality and the mystery of life, such as in stories where there is no cure, where the person is dying, or the impairment will remain chronic (Frank, 1997). “When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real” (Frank, 1997, p. 94).

The chaos narrative: Mute illness

In contrast to the previous metaphors, the plot of the chaos narrative imagines life never getting better. “Stories are chaotic in their absence of narrative order … without sequence or discernable causality” (Frank, 1997, p. 97). The teller of chaos stories is the wounded storyteller living the chaos, but unable to create a story from this. The person is unable to distance themselves from the chaos and reflect on the situation and storytelling is impossible. These stories can only be lived and not literally told, although the voice can be identified and the story reconstructed (Frank, 1997). Thus, the chaos story presupposes lack of control or a sense that no one is in control (Frank, 1997). In the chaotic narrative the person has no control of life’s contingency, has difficulty finding comfort from the pain and suffering, lacks desire, and dissociates from self (Frank, 1997).

The chaos narrative is the most difficult to hear and listen to, as the listener comes to terms with the reality of what is being said (Frank, 1997). Listeners can deny the story and believe that, in similar circumstances, they would find a way out. There is no clinical category “for living a life of overwhelming trouble and suffering” (Frank, 1997, p. 112). The chaos narrative, if denied, is replaced by the restitution narrative, in which the person living a chaotic narrative is seen as depressed and can be fixed. When the experience of overwhelming trouble and suffering is denied, the chaos is compounded. The denial of this type of story is a denial of the storyteller, the consequence of which is that the storyteller is denied care (Frank, 1997). Therefore, the rebuilding of life and the telling of new stories requires an acceptance of the chaos narrative” (Frank, 1997).
The quest narrative: Illness and the communicating body

In the plot of the quest narrative, the illness emerges as a journey, in which something can be gained from the illness experience (Frank, 1997). The interruption of past, present and future is reframed as a challenge. “The genesis of the quest is some occasion requiring the person to be more than she (sic) has been, and the purpose is becoming one who has risen to the occasion” (Frank, 1997, p. 128). “The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking” (Frank, 1997, p. 117). Therefore, the quest narrative provides the hero with their own voice in the telling of the hero’s journey.

Frank (1997) summarises Campbell’s (1972) phases of the hero’s journey, to explain the quest narrative. The first phase, the departure, occurs when the first threshold is crossed and the hero begins the illness journey. The second phase, is the initiation or the road of trials, in which the hero, through these trials, undergoes a transformation. The final stage is the return, when the hero is marked by the experience and lives in a world they have travelled beyond, as a master of two worlds. The end of the journey brings the “boon”, in which the hero has developed some insight by the experience, which must be passed on to others (Frank, 1997).

The facets of the quest story are memoir, manifesto and automythology. The memoir, involves telling the story with other events in the hero’s life and can be described as an interrupted autobiography. There is no special insight from the illness journey; the insight is the incorporation of the illness into the person’s life. The manifesto, involves the hero on their return calling for social action, because they want to use their experience of suffering to facilitate social change and move others forward with them. For the automythology, the dominant metaphor is the phoenix, reinventing itself from the ashes of its own body. Heroes reinvent themselves after trauma or illness. Like the manifesto, the hero reaches out to others, from their own experience, but the language is more personal than political, so that individual change not social reform is emphasised (Frank, 1997). The quest story is about finding voice in self and others, through recollection of events, through solidarity with other fellow suffers and through inspiration. Frank explains (1997, p. 136) that “the quest narrative recognizes ill people as responsible moral agents whose primary action is witness: its stories are necessary to restore the moral agency that other stories sacrifice”.

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It is possible that all three types of the illness narratives will be told in the stories of suffering in this study as the journey unfolds from diagnosis until eventual death. These typologies assist in understanding the metaphor of suffering as it appears at different points in time within a configured narrative. In addition to identifying the types, the relevant facet of the quest metaphor may assist in revealing how the family members create meaning from the stories told.

Frank (1997) cautions that human illness and suffering, even when told as a quest, always returns to mourning. “The “boon” is gaining the ability to mourn, not for oneself only, but for others” (Frank, 1997, p. 136). Through storytelling the family members may be capable of the boon and develop a testimonial through which others stories of mourning can be articulated.

In summary, Frank (1997) suggests illness stories are testimonies of the experience of suffering and illness. “Testimonies are initiated by suffering, and suffering comes to understand itself by hearing its own testimony” (Frank, 1997, p. 169). The stories become testimonies when another witnesses that story. The teller is required to be in a relationship with the listener, where the only mode of receiving the testimony is being with the teller. As Frank (1997, p. 144) explains, the “listener must be present as a potentially suffering body to receive the testimony which is the suffering body of the teller”. The contents of these testimonies are valuable “for the teller’s re-ordering of her (sic) life story, as guidance to others who will follow, and to provide caregivers with an understanding of what the ill experience” (Frank, 1997, p. 140).

Frank’s (1997) wounded storyteller metaphor provides the context in which the testimonies from the family members in this study are elicited through myself as the researcher witnessing the stories. My own story provides a more in-depth understanding of the experience and the ability to witness the stories more emphatically. Using Frank’s (1997) typologies as a guide for the interpretation of these stories, the testimonies will provide some understanding for others with similar stories. Further, to this those engaged with caring for this group of people will be enabled to understand the experience of family members. For these reasons, Frank’s metaphor of the wounded storyteller provides a guide to interpret the stories of suffering from the family members in this study.
Whilst Frank (1997) provides a typology and context within which to interpret the illness narratives, he provides no guidelines of how to create or emplot the narrative and, like Klienmann (1988), the narrative is related to the discourse of the illness narrative. Mattingling (1994) suggests looking beyond the discourse of the illness narrative and consider the development of a narrative structure. He asks for some method for emplotment of these illness narratives. This concept of emplotment has been discussed by Polkinghorne (1995) and Emden (1998b) in the previous section of this chapter. These scholars support the use of narrative configuration as a means of emplotting and creating a narrative from the stories of suffering told in this study.

Therefore, the illness narrative provides guidance for this study for the following reasons. Kleinman (1988) provides a perspective for facilitating listening to a person’s story of suffering. Frank (1997), with his representation of the three types of illness narratives, provides a framework to describe the narrative of suffering for the family members in this study. In addition, Frank (1997) provides support for the healing and emancipatory power of telling the story of human suffering. The testimonies of the patients provide the context for the person, to create meaning out of the experience of suffering. He also reinforces my own position in the study, where the testimonies of the storytellers are understood within my similar wounded storyteller narrative, creating a more in-depth, sensitive understanding of the meaning of the wounded stories.

**SUMMARY: NARRATIVE MODELS OF ANALYSIS**

In summary the models discussed provide guidance for this study in the following way. Mishler’s (1986 a,b) and Riessman’s (1993) emphasis on the interview in narrative, highlights the value of the open-ended interview and the importance of the relationship between the family member and myself in creating the story as well as the context of the interview. In addition the interview is seen to have an emancipatory function for the participant. Riessman (1993) further contributed to this understanding by providing guidelines from which the interview can be analysed. Lieblich, Tulval and Ziblier’s (1998) model provides methods of reading narrative and two of the methods, categorical content and holistic form, provide a framework for interpreting the narratives in this study. Polkinghorne’s (1995) narrative configuration provides direction on how to create a plot or core story from the data and could be a useful adjunct to the holistic
form and the categorical content form of analysis, particularly if using Emden’s (1998) method of analysis.

The illness narrative, whilst not giving a clear direction as to a method of analysis, supports the importance of people narrating their personal story of suffering in order to create meaning out of the experience. The testimony of the personal illness narratives increases the understanding of suffering for others. Frank’s (1997) three typologies of the illness narrative and facets of the quest typology provide a reference from which to interpret the narratives of suffering in this study.

**The Narrative Analysis Framework Applied to this Study**

The previous section discussed narrative models of analysis that could provide a framework for the research design for this study. Aspects of the models discussed were selected to provide the analytical framework for this study. These aspects include Mishler’s (1986) and Riessman (1993) interview as narrative, Riessman’s (1993) guidelines for conducting a narrative analysis, Polkinghorne’s (1995) narrative configuration model further developed by Emden’s (1998) core story development, Lieblich et al.’s (1998) concept of holistic form and the pattern of the story or structural analysis, analysis of the narrative as a whole. Further to this Taylor’s (2006) method of computer-assisted thematic analysis and the use of NVivo8 software to collate and organise the themes, assisted in the development of the core stories. The stories of suffering associated with Frank’s (1997) wounded storyteller typologies will be use as a guide for interpretation and analysis. Table 4.4 links the steps of narrative analysis for this study with specific processes and relevant authors.
Table 4.4: The Narrative Analysis Method

<table>
<thead>
<tr>
<th>Authors</th>
<th>Step 1 Data collection</th>
<th>Step 2 Creation of the Core Story</th>
<th>Step 3 Identification of Patterns</th>
<th>Step 4 Creation of Subheadings</th>
<th>Step 5 Development of the Individual Narrative</th>
<th>Step 6 Thematic Analysis Creation of the meta-narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Riessman (1993)</td>
<td>Telling</td>
<td>Transcribing and analysing</td>
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<td></td>
<td></td>
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<tr>
<td>Misler (1986)</td>
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<td>Riessman (1993)</td>
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<tr>
<td>Emden (1998)</td>
<td></td>
<td>Creation of family members’ stories</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Lieblich et al (1998)</td>
<td></td>
<td>Sectioning of events in the story with the use of subheadings</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Taylor (2006)</td>
<td></td>
<td></td>
<td></td>
<td>Narrative configuration: the process of emplotment to produce a core story</td>
<td></td>
<td></td>
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<tr>
<td>Polkinghorne (1995)</td>
<td></td>
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</tr>
<tr>
<td>Taylor (2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Computer-assisted thematic analysis of stories in addition to NVivo8</td>
<td></td>
</tr>
<tr>
<td>Frank (1997)</td>
<td>Wounded story teller guided the steps and processes associated with this method</td>
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</table>

**STEP 1 - TELLING:**

*Data Collection*

As has been discussed previously, audiotaping and transcribing of the interview is considered essential for narrative analysis (Mishler, 1986a, 1986b; Riessman, 1993). The family members’ stories in this research were all recorded on an iPod and the recordings were copied to a CD. Due to the length of some of the interviews and my own limited technical skills in transcribing, a professional transcriber was employed to transcribe the interviews. The transcriber was cognisant of the need for confidentiality and was careful not to breach any of the ethical safeguards of the study. She had been involved with sensitive and confidential transcribing in the past; transcribing the court
reports for children who had been victims of abuse. Once the stories were transcribed the transcripts were sent to the family members for member checking.

**Interview Process**

The interview process within narrative inquiry favours the open-ended interview (Frank, 1997; Kleinman, 1988; Mishler, 1986a, 1986b; Riessman, 1993; Sandelowski, 1991). The open-ended interview requires the interviewer to provide a relaxed atmosphere and formulate questions, which result in open and undisturbed communication (Silverman, 2006). This method of interviewing requires the researcher to provide the participant with the opportunity to speak and create storied accounts of their experience (Mishler, 1986a, 1986b). This opportunity to create stories constructs and produces meaning from the experience, which in turn, empowers the family member (Frank, 1997; Kleinman, 1988; Mishler, 1986a, 1986b; Riessman, 1993).

Riessman (1993) and Mishler (1986a, 1986b) both emphasise that the context in which the interview is conducted can influence the final narrative or stories. For the purpose of this study, the family members decided where, when and how the interview would be conducted. The majority of the interviews were conducted in the family member’s own home. Five of the family members chose to be interviewed in other settings, which were organised by myself to be neutral settings, which provided a degree of privacy such as interview rooms, units and hotel accommodation. The majority of the interviews were face-to-face interviews, although some were conducted by phone due to the isolation and distance of some of the family members and my own inability due to lack of resources, time and finances, to access these family members personally. Some of the family members, wanted a face-to-face interview despite the distance, therefore I travelled to conduct these interviews, which were all in New South Wales, Australia. We negotiated a suitable time in which to conduct the interview in which I would have the time and flexibility to travel the distance. Because of this, some of the interviews were conducted 6 to 18 months after the family members had been recruited into the study. This time frame, as mentioned previously, also gave me the opportunity to honour and reflect on the individual stories.

As discussed in the ethics section of this chapter, my own experience of having an adolescent family member die of cancer influenced the context of the interview and the stories told. Within this context, experience is constructed according to who is the
listener and how the self wants to be represented by the listener (Riessman, 1993). Narrative authors suggested that I, as the listener having a similar experience, would facilitate in-depth rich description of the experience (Bruner, 1987; Frank, 1997; Löytyniemi, 2001; Mishler, 1986b).

I commenced the interview by reiterating my research intentions, and acknowledging to the family members that telling the story of the AYA who had died, may be painful. The tissue box was present, just in case. The family members were advised that they could stop recording at any time if they found the story telling too difficult. All family members finished telling their stories without having to stop the recording. I reflected that this was because of the narrative method and the use of open-ended questions. The family members were able to control the interview and tell the story within their own safe boundaries. None of the interviews resulted in the family member being overwhelmed with emotion or requiring professional counselling.

As guided by Misler (1986 a,b) and Riessman (1993) I facilitated the interview by asking open-ended questions and asked for an extended account of the experience. Initially, the study had one broad question to facilitate the creation of the narrative with a number of probe questions if the family members were having difficulty telling their story. Table 4.5 identifies these questions.

**Table 4.5 Open-ended Interview Questions**

<table>
<thead>
<tr>
<th>Broad question</th>
<th>Can you tell me your experience of (AYA’s name) from the time he/she was diagnosed until he/she died?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probing questions</td>
<td>Can you tell me how the diagnosis of cancer impacted on you and your family?</td>
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<tr>
<td></td>
<td>Can you tell me what it was like for you and your family when (name) was receiving treatment?</td>
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<tr>
<td></td>
<td>How did you and your family deal with the information that treatment was no longer effective?</td>
</tr>
<tr>
<td></td>
<td>How do you believe the health system influenced the care that you received?</td>
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<tr>
<td></td>
<td>Can you tell the things that health professionals did that helped when (name) was receiving treatment and during the end of life phase of the cancer journey?</td>
</tr>
<tr>
<td></td>
<td>What were some of the things health professionals could have done better to help during the treatment phase and end of life phase?</td>
</tr>
<tr>
<td></td>
<td>Can you tell me about the experience of (name) dying?</td>
</tr>
</tbody>
</table>
I encouraged the family members to develop their own narrative with minimal prompts. This is confirmed by Elliot (2005), who highlights the risks of interrupting family members’ stories and that the most important quality for a narrative researcher is to be a good listener. As a result, there was little structure in the interviews. During the process of the interviews, it became apparent that the family members were intent on telling the story of their loved one in their own words and at their own pace, therefore, the interviews were guided by this. The probing questions that had been developed were not required and in order to keep the stories flowing, I was only required to give verbal and nonverbal cues and occasionally reflect on what the person had said. In order to respect the stories further, there was no time limit. The average duration of the interview was 1 hour and 45 minutes with a minimum duration of 45 minutes and a maximum of three hours and 15 minutes. The phone interviews tended to be the shortest and to have a more narrative plot or story line. It is proposed that this relates to the family members in the face-to-face interview feeling prompted to tell their story by my nonverbal cues and my ability to convey empathy more easily, and to my physical presence with the person as they told their painful story. Despite this difference all the stories in this study spoke of similar experiences. This suggests the phone interview is an effective method for uncovering stories of suffering.

The stories that unfolded had elements related to the aims and objectives and provided rich in-depth accounts of the experience being studied. The family members sought to share poems, pictures of their loved one, and intimate details of their experience of a young family member living with and dying of cancer. Given the sensitive nature of this study, and as mentioned in the ethics section of this chapter, all family members were contacted by phone a week or two after the interview to thank them and to see if any issues had resurfaced, because of the interview process. All family members welcomed the opportunity to tell the story of the AYA family member and expressed a wish that the stories they told would somehow influence the care that future AYAs with cancer and their families received.
STEP 2 - CREATION OF A FAMILY MEMBER’S STORY

The first stage of the transcribing and analysis involved creating a story of the personal narratives.

The story creation was initially commenced by selecting and combining elements of Riessman’s (1993) guidelines for transcribing and analysing and Emden’s guidelines (1998b) for the development of a core story. In addition, I utilised Polkinghorne’s (1988, 1995) concepts of temporality and sequencing events, so the story has a beginning, a middle and an end. From these authors, I selected the following steps as a method of story creation for this study. The steps are represented in Figure 4.1.

Application of the creation of the stories to this study

To familiarise myself with the family members’ stories I listened to the CDs approximately one month after the initial interview. I thought this time frame would give me the opportunity to distance myself from the story and not become emotionally overwhelmed, which may have occurred if I had listened to the recordings too soon after the interview. Listening to the recording gave me the opportunity to appreciate the emotional content of the story by listening to the tone, the silences and the flow of the interview. Once the recordings had been transcribed as suggested by Emden (1993b)
and Riessman (1993), I read and re-read the written transcripts within an extended time frame of approximately three months.

I examined my possible influence on manipulating the direction and content of the story line. My verbal input was minimal with occasional encouragers such as “go on,” “yeah,” “so, what happened?” When I did use the occasional probing question the question was rarely finished, before the family member freely returned to the story. Therefore my comments and questions were deleted from the text, as suggested by Emden (1995b), to present the text of the story.

In the next step, words and sentences that did not relate to the experience of the family member having an AYA living and dying of cancer were deleted from the transcript. I then re-transcribed the transcript and those elements of the transcript, which had a narrative form and related to the aims and objectives of the study, were included in the new transcript. During this stage of the development of the core story, I sequenced the events into a temporal order of a story with a beginning, a middle and an end. The beginning was the diagnosis, the middle was the events that occurred during treatment, and the end was the dying and death.

This new transcript was read to see if the story made sense. I then repeated these steps several times, returning to the full transcript as often as possible to ensure all key concepts were retained and extraneous content was eliminated.

The steps in this story development allowed me to familiarise myself with the transcripts and become immersed in the stories. Each step required that I revisit the transcripts and honour the family members’ stories. By this method, content specific to the research aims was captured.

**STEP 3 - IDENTIFICATION OF PATTERNS OR TURNING POINTS**

Lieblich et al (1998) further extend the creation of the core story with their description of holistic form, in which narrative patterns are identified within the stories. Within Lieblich’s et al (1998) holistic content model, structure can be applied to the stories to identify phases, patterns and turning points in the story/stories.
Application of Lieblich’s et al (1998) holistic content model to this study

I re-read the stories to identify elements in the stories and turning points with a sequence of progress and decline in the stories. Within this analysis, it became clear that family members told their stories in transitional periods or turning points. With amazing regularity family members identified four distinct phases or turning points within the personal narratives, with no prompting from me.

These phases or turning points related to the cancer journey which have been identified by Armstrong-Coster (2004): Departure (diagnosis), Exploration (Treatment), Anticipation (Remission) and Destination (Death and Dying). For those family members whose family member did not experience a remission, the representations identified three phases of the Departure, Exploration and Destination.

**STEP 4: CREATION OF SUBHEADINGS**

Using Taylor’s (2006) ‘read and section’ phase of her computer-assisted approach to thematic analysis, I created subheadings from the family members stories. I did this as described by Taylor (2006), by re-reading the story as it scrolled down the computer screen. I then sectioned parts of the transcript that were specific to events relating to the research aims and objectives with subheadings. These subheadings were descriptions of the experience for the family member as they occurred within the identified phases of the cancer journey.

**STEP 5: DEVELOPMENT OF THE PLOT OR CORE STORY**

Polkinghorne (1995) describes narrative configuration or emplotment, as the development of a plot, which results in a story with a beginning, a middle, and an end. Polkinghorne (1995) provides minimal guidance on the configuration of the core story so I developed the following steps, informed by Polkinghorne’s work, to emplot the events and happenings of the family member’s story to form a plot or organised whole core story. This is represented in 4.2.
**Application of narrative configuration to this study**

For the purpose of this study, the temporal range of the story had been identified from the aims and objectives of this study. The temporal range includes the time from diagnosis through to the actual death. The events that I included in the plot related specifically to the family member’s experience of their AYA living with and dying of cancer. These events were identified previously within the family members’ transcripts and the events had been configured within these transcripts. The purpose of the configuration in this stage of the analysis was a core story that summarised the events using narrative configuration to emplot the events.

Using the subheadings created in Step 4, I summarised the sections related to these subheadings to create a plot or core story. I continually checked this unfolding plot against the already created family members’ stories, to ensure the family member’s experience was being properly represented within the configured plot. I had previously sequenced the events within this configured plot temporally, with a beginning, a middle, and an end in the creation of the family members’ stories. The final configured plot or core stories were the individual and family member’s stories.

Chapter five presents four exemplar core stories from family members who provided in-depth and rich descriptions of the cancer and dying experience for the AYA and themselves. The remainder of the chapter provides reflections on the other family members’ core stories. To read the full version of the other family members core stories refer to Appendix J. The core story is represented in the first person. Helen and Geoff, mother and father of Mick, despite separate interviews their stories were combined
because of the similarity of the accounts and events. The core stories were emailed to
the family members who were asked if the story ‘rang true’ for them and if it required
any changes. Only one family member asked for minimal changes, and feedback
suggested that the core stories rang true for the family members in this study.

**STEP 6: THEMATIC ANALYSIS: CREATION OF THE META-NARRATIVE**

The purpose of thematic analysis within this study was to present the narratives of this
study as defined by Polkinghorne (1988). He defines narrative as “a scheme of multiple
stories that organise events and human actions into a whole” (p.18). Authors who have
described thematic analysis include Polkinghorne (1993) Lieblich et al (1998) and
Taylor (2006). Polkinghorne describes paradigmatic analysis of narratives in which
stories are analysed using paradigmatic analytical procedures, to produce categories out
of common elements within the stories. Polkinghorne provides no real guidance on how
to conduct this form of analysis.

Lieblich et al (1998) describes the categorical content form of analysis as a form of
content analysis in which categories are defined and part of the narrative are classified
and gathered into these categories. They provide some steps on how to conduct this
form of analysis. Taylor (2006a, p. 459) simply describes thematic analysis as “a
method for identifying themes, essences or patterns within the text”. She also provides a
step-by-step guide on how to conduct a computer-assisted thematic analysis. Whilst
Lieblich et al (1998) provides steps on how to conduct a content analysis for the
purpose of this study, I felt Taylor’s (2006) computer-assisted approach provided a
more systematic and detailed description of how to conduct this form of analysis.
Therefore, it was decided to use Taylor’s approach in the thematic analysis for this
study, because of its simplicity and the step-by-step method and because I had the
opportunity to be guided in the method by the author who was my supervisor at that
time. Taylor’s (2006a) computer-assisted method of thematic analysis is represented in
Figure 4.3
**Application of Taylor’s computer-assisted thematic analysis to this study**

I had already completed phases 1-3 in steps 2 and 4 of this study, so the thematic analysis for this study commenced at Step 4 of Taylor’s model. Transitional phases and turning points had been identified in Step 3 - the holistic form content analysis, in this study. Therefore, I decided to look for themes and subthemes within each transitional phase related to the relevant turning point of each core story.

In order to look for explicit and implicit themes, I read the sectioned transcript with the subheadings and considered how these subheadings and sections related to my research aims and objectives. At this stage of the analysis, I did not identify these themes but I had developed an understanding of the possible themes that may emerge in the future analysis from my deep immersion in the family members’ stories.

In order to collate the themes, I initially copied and pasted each sectioned family member’s story into a separate folder named ‘collective analyses. With the duplicated copy of the sectioned story, I scrolled through each family member’s story and deleted everything except the subheadings. In order to know whose story the subheadings came from, when finding common themes and subthemes within the collective analysis, the name of the family member was written in brackets after each subheading.

The subheadings were then printed. I reviewed this printed list of subheadings and, looking at my aims and objectives, asked myself how these subheadings related to my research interest. I then identified those subheadings that appeared to have a common element or theme. These common themes were identified, given a name and highlighted with a specific coloured highlighter pen using the colour coding method described by Taylor (2006a). I used the same coloured highlighter pen to mark subheadings that were connected to a common theme. The themes were categorised within each of the transitional phases and turning points identified in the created stories. This process was
repeated for each family member. Subheadings that were common across the family members’ stories were colour coded according to the colour already used to identify the theme. If new themes were uncovered in the analysis of another family member’s story a different highlighter pen was used and the common subheadings slotted into this new coloured theme. As such, common themes were identified across the family members’ transcripts.

For example, a theme that was identified in the Exploration stage was “living the quest.” This theme was named and highlighted with a blue highlighter pen, the subheadings which related to this theme in the family members’ stories were highlighted using the same coloured blue pen. For example some of the subheadings associated within this theme included: remembering how strong Paul was and that he never complained; seeing Thomas on his mobile phone just after his amputation; and describing Brenton Duncan’s optimism for life after the amputation.

I continued with this process with each individual story until I reached a point in the analysis where it was obvious that there was a saturation point of the number of themes from the stories I had colour coded. To further assist the process and continue with the analysis of all the family members’ stories I used a computer software package NVivo8 to continue with the thematic analysis. I imported all the sectioned stories with the subheadings into NVivo8. I then developed a hierarchical tree of nodes with the cancer journey phases and themes that had already been created. Working with the stories that had already been analysed and the remaining stories with the subheadings that had been imported, I copied the section of the stories that had a commonality with a created theme into that tree node. If another theme was noticed in the remaining family member’s stories I created another tree node within the relevant stage. Once all the family members’ stories had been analysed and the themes created I opened the relevant theme tree node and selected in-depth examples of the collective themes. During this process some of the themes were compressed into one theme. Furthermore it became obvious that some of the themes contained subthemes that were also created within the hierarchical tree node. This resulted in the creation of 23 themes, four within the Departure stage, six within the Exploration stage, one within the Anticipation stage and 12 within the Destination stage. The themes and the subthemes are presented in the analysis and interpretation chapters in this thesis: Chapter 7 discussing the Departure, Exploration and Anticipation stages and Chapter 8 discussing the Destination stage.
Figures 4.4 provide a visual representation of the steps that were involved in the creation of the core stories and the thematic analysis.

**LIMITATIONS WITHIN NARRATIVE INQUIRY**

Riley and Hawe (2005) assert that a primary weakness of narrative inquiry is that it is retrospective and the length of time for analysis and presentation of results can be a disincentive. The nature of this study was retrospective, with no exclusion criteria related to the years since the death of the AYA. For example, in one family interview the family member’s son and brother had died over 20 years previously; for some families, members were prepared to wait for an occasion when I was able to do a face-to-face interview. However, Riley and Hawe (2005) argue that the retrospective nature of narrative provides the opportunity to have deeper understanding of the experience of the family members in the study. This was evident in this study where the retrospective nature of the study resulted in thick descriptions of the family member’s experience that is cognisant with the aims of this study. The resultant thick descriptions provided the stories that could be interpreted from an in-depth understanding of the experience.
Another perceived limitation is the blurring of interpretive boundaries between the family member and myself, due to my in-depth understanding of the family members’ experiences (Riley & Hawe, 2005). As mentioned by Atkinson (1997), this can result in the researcher having a strong interpretation, without sufficient links back to empirical data, or to have a weak interpretive role, with lack of attention to the social context and interaction, resulting in a celebration rather than an analysis of the stories. Riley and Hawe (2005) suggest this criticism is applied when researchers are unable to define and defend their interpretive framework for analysis of the data. In addition, introspective reflexivity is required to analyse the dynamic between the researcher and the researched. In this way, the researcher’s location within the study is made transparent.

The blurring of the interpretive boundaries, which may have been an issue in this study have been discussed in the ethics section of this chapter. I attempted to address this limitation by defining and defending the interpretive framework developed for this study. The interpretive framework was developed by using authors who are prominent and respected in the in the field of narrative inquiry. These authors also provided information on some of the pitfalls associated with narrative analysis. In addition, as a researcher who had a similar experience to the family members, I was always mindful of this possible blurring of boundaries and regularly debriefed with my supervisor and a critical friend (my husband) as a method of introspective reflexivity.

Moreover, “interviews do not appear to give us direct access to the facts or events. Interviews do not tell us directly about people’s experiences, but instead offer indirect representations of those experiences” (Silverman, 2006, p. 117). Riessman (1993), Mishler (1986a, 1986b) Sandleowski (1991, 1993) Bruner (1987) and Lee and Poole (2005) all support this notion, that the person’s representation of experience are reconstructions of that experience, with the person selecting elements of the experience which create meaning for that person and, as such, they are not ‘true’ replicas of the facts or events. In addition, they contend the elements of a story can change with the telling to the retelling and the context in which the story is told.

Bruner (1987) explained that life stories have the power to direct the person’s life, and the person’s story becomes the narrative by which a person shapes their life. The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become the experience of those lives … life moves on, stories change with that
movement, and experience changes. Stories are true to the flux of experience and the story affects the direction of the flux (Frank, 1997, p. 22).

As such, narrative inquiry only captures a person’s experience at a particular point in time and representations of the experience will change over time as subsequent experiences influence the person’s interpretation and recall (Lee & Poole, 2005). Therefore, the interviews in this study are representations of the meaning the family members have created from their experience, at the particular time and in the particular context of the interview situation. The events that have created the story are those elements of the experience, which the family member has selected in order to create meaning from the experience.

In addition, narratives are constructed by both myself and the family member, in that the questions asked influence and shape the content and direction of the story (Lee & Poole, 2005). Questions are framed according to what I require from the experience. In this study, I was interested in how families create meaning from the experience of a young family member living and dying of cancer, therefore, the questions reflected what I as the researcher was wanting to understand about the experience. This can create the problem of rigour for the research, as Bruner (1987) questions the criteria we use to determine the rightness of a story. The instability of autobiographical accounts make them “highly susceptible to cultural, interpersonal, and linguistic influences” (Bruner, 1987, p. 14). In other words, “meaning is fluid and contextual, not fixed and universal. All we have is talk and texts that represent reality partially, selectively and imperfectly” (Riessman 1993, p. 15). Sandelowski (1991) extends the argument further, by stating that narratives are “truthful fictions”, in that the interpretation of what happened, and the making up of what something means, all involves human fabrication. As such, “no-one method or perspective has the insight into ‘truth’” (Overcash, 2004, p. 19).

The research aims and objectives posed in this study all reflect what I as a researcher was seeking to understand from the experience of the family members; the stories that were told all reflected this. The reader can only assume the stories are true representations of the person’s reality as it was interpreted through the cultural, linguistical and interpersonal context for that particular person at that particular time. The stories are, as Sandelowski (1991) says, ‘truthful fiction’ in that the family members in this study are telling their story and their truth as it has been interpreted through their reality.
“A similar process occurs with transcribing, analyzing and reading” (Riessman, 1993, p. 15). Mishler (1986a, 1986b) and Riessman (1993) both discuss the issues of boundaries of stories or what researchers chose to interpret as the beginning and end of a narrative. The boundaries determine what part of the family members stories I include in the final narrative. My “interpretation of the stories are aimed at increased understanding and are partial truths with the aim of believability“ (Riessman, 1993, p. 23). Narrative analysis is not objective but subjective and the position of the researcher is considered as part of this interpretation (Riessman, 2002, p. 704).

Therefore “the ‘trustworthiness’ of narrative accounts cannot be evaluated using traditional correspondence criteria. There is no canonical approach to the validation in interpretative work, no recipes or formulas” (Riessman, 2002, p. 706). Narrative is not the truth, because there are multiple interpretations of the same event. With each stage of the analysis of the story, the story is altered by a number of filters. As such, the elements of the story can be expected to change from the telling to the retelling of events (Sandelowski, 1991). The final meta narrative is the narrative created by the myself through the stories of others (Gilbert, 2002). This meta narrative has, in turn, been interpreted through the methodological framework chosen for my study and is just one way of analysing and interpreting the data (Lee & Poole, 2005; Lieblich, et al., 1998).

The research aims in this study created the boundaries of the story, and determined what was included in the final narrative. Only those elements of the story that provided a greater understanding of the research aims and objectives were selected for the final narrative. The final meta - narrative was filtered through my understanding of these research aims and objectives, in addition to my own connection and empathy with the family members stories. This influenced my interpretation of the stories, the boundaries of the core narratives and the themes that have been identified. Having an understanding of these boundary issues in narrative resulted in me being mindful of my own position and subjectivity within the research process. Therefore I sought to continually maintain the trustworthiness of the research process through the process of introspective reflexivity, and strict adherence to the methodological process used in this study. Thus, creating a transparency for the reader of the research of the dynamic between me and the family member.
As such, narrative truth is a lifelike, intelligible and plausible story, the trustworthiness of which is based in the credibility of the story (Gilbert, 2002; Sandelowski, 1991). Within storytelling, the narrator strives for “narrative probability - a story that makes sense; narrative fidelity – a story consistent with past experience or other stories; and aesthetic finality – a story with satisfactory closure and representational appeal” (Sandelowski, 1991, p. 165). The narrative standard of truth “is not how to know truth, but rather how experience is endowed with meaning” (Sandelowski, 1991, p. 165). As such I am interested in the interpretation of meaning, not truth, from the stories that the family members tell.

To impose validity testing on narrative research results is a preoccupation with the empirical, rather than an understanding of narrative truth (Sandelowski, 1991). Sandelowski asserts that to impose strict criteria to narrative analysis “we remain in danger of succumbing to the ‘illusion technique’ of making a fetish of it at the expense of perfecting a craft and making rigour an unyielding end in itself” (Sandelowski, 1993, p. 1).

Despite the limitations of narrative described in this section of the chapter there is an assumption of narrative truth, which is dependent on the credibility of the story. This study sought to interpret the meaning of the experience for the family members and develop credible stories, which could be evaluated as trustworthy within the research community. This concept of trustworthiness and how it has been applied to this study is discussed in the next section.

**TRUSTWORTHINESS IN NARRATIVE INQUIRY**

The previous section highlighted some of the limitations associated with narrative inquiry. The dominant argument relates to the inability to know with any certainty that the stories told are, in fact, true representations of reality. Some authors have argued that it is almost impossible to determine the validity of a story (Bruner, 1987; Koch, 1998; Lee & Poole, 2005; Mishler, 1986a, 1986b; Riessman, 1993; Sandelowski, 1991, 1993; Silverman, 2006). Despite the limitations associated with narrative research and the argument for the demise of criteria in evaluating the validity of narrative research, Emden (1995) and Sandelowski (1999) (as cited in Taylor, 2006b) advise on the practical realities of keeping qualitative research alive. The authors provide criteria of
goodness, for those researchers involved in evaluating the worthiness of the research study. In other words, the research study needs to be checked for the degree to which it can be trusted by the research community as a worthy product, because the research study must be plausible and meaningful to family members and peers (Wilson, 2007). This process is achieved through the rigour and trustworthiness of the study.

This section describes the concept of rigour and trustworthiness as it relates to narrative inquiry, by tracking the evolution of various authors’ ideas, as they have struggled to define and apply the criteria of trustworthiness to qualitative research studies. These criteria assure recipients of the research that they can rely on the findings, because they are confident in the trustworthiness of this study, as described by the transparent representation of the research process. Given that there are many contributors to this discussion, the main authors’ work will be highlighted in this section. In conclusion, the work of Reissman (1993) will be used, to apply trustworthiness measures to my study.

Trustworthiness has been defined by Moss (2004) as “acts of integrity that researchers take to ensure they seek truth by contextualizing their studies and disclosing all relevant procedures used in the study” (p 371 as cited in Wilson, 2007, p. 109). Mishler (1990) argues that the evaluation of the trustworthiness of a study is based on the skilled researcher’s understanding of their field of inquiry, to make claims for their research product and have the product accepted by other skilled researchers as ‘good science’. Burns and Grove (1997, p 64) argue that rigour in qualitative research “is associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data in the subjective theory development phase” (as cited in Taylor, 2006b, p. 402). This results in an open and transparent study, which can be scrutinised by others, to determine methodological accuracy or the worthiness of the study (Taylor, 2006b).

The criterion for trustworthiness in qualitative research was introduced by Guba and Lincoln (1981 as cited in Taylor, 2006b) and include credibility, fittingness, auditability and confirmability. On the other hand Bailey (1996) argues that trustworthiness criterion accepts the positivist criterion as superior and attempts to establish qualitative research as acceptable within the scientific community (Bailey, 1996).

Therefore, alternative ways of determining the quality of knowledge have now emerged, which reflect the epistemological differences between the positivist and interpretive...
paradigm. Research findings are evaluated for trustworthiness, credibility, authenticity and/or goodness (Bailey, 1996). Lincoln (1990, as cited in Bailey 1996) replaced the criterion of trustworthiness, based on the ontology of positivism or truth, with authenticity, based on the relativism of the qualitative model. The term ‘goodness’ is associated with the need to differentiate between valid and invalid qualitative research (Bailey, 1996). Within narrative inquiry, the terms trustworthiness and credibility have transformed validity from an objective reality to a process of confirmation or validation (Bailey, 1996). Trustworthiness, not truth, moves the research process into the social world (Riessman, 1993). This process of confirmation or validation involves making the research process visible for systematic scrutiny (Bailey, 1996; Mishler, 1990; Polkinghorne, 1988; Riessman, 1993; Sandelowski, 1993). No set rules confer credibility, rather, as Sandleowski (1993) asserts, trustworthiness is a matter of persuasion, where scientists have made their practices visible, and, therefore, auditable to the research community.

Within the context of narrative inquiry, Koch (1998), refers to the outcome of the research process as the research product. She introduces the notion of the legitimacy of the research process, which does not show us what to do but questions what is going on in relation to the methods. She claims “if the research product is well sign-posted, the readers will be able to travel easily through the worlds of the family members and the makers of the story and decide for themselves, whether the story is a legitimate research endeavour” (p. 1182). As such, she asks us to consider the story as a legitimate research product. She discusses criteria for rigour based on the work of Lincoln and Guba (1985), which includes credibility, transferability and dependability.

The credibility of the research product is related to how the interpretations of the narrative present faithful descriptions. Credibility can be achieved by providing the readers with the original text or one explained through the researcher’s interpretive model. Within the criterion of transferability, the original context must be described, so a decision about transferability to similar research contexts can be made. She maintains dependability can be maintained through a research audit or by maintaining a decision trail, which entails the theoretical, methodological and analytical choices made throughout the research study. She believes rigour is maintained by producing vital stories, because stories that recreate the mood and the setting make the experience come alive. These stories are created by organisation, creativity and time.
Koch (1998) revisits the limitations of people’s stories being stories as told at particular points in time and within different contexts and the researcher uncovers the past according to their interpretations of the story which may not be a true representation of the story. This can lead to competing interpretations as the interpreter of the text engages in a dialogue with the text or as a hermeneutic conversation. The goal of this hermeneutic conversation is the intersection of the author and the interpreter with the dialogue and to create meaning and understanding from the stories. Koch contends this process of creating meaning and increasing understanding should be considered as research. The evaluation criteria can be incorporated within the research product “through detailed and contextual writing and a reflexive account of the actual research process” (Koch, 1998 p 1189). This reflexive account is achieved by the readers being aware of what is going on in the research process. This enables the readers to understand the world of the family members and the researcher’s interpretation of the family members’ stories and decide for themselves if the narrative is a legitimate research endeavour.

Elliot (2005) discusses the concepts of reliability and validity within the context of narrative inquiry. “While reliability is generally defined as the replicability or stability of research findings, validity refers to the ability of research to reflect an external reality or to measure a concept of interest” (Elliot, 2005, p. 20). A distinction is made between internal and external validity, where internal validity refers to the ability to produce results, which are not simply part of the research design, whilst external validity refers to the generalisability of the research findings to the broader population. These terms originated within the quantitative research method with the concept of measurement. This concept of measurement fits uneasily within the qualitative framework, with the emphasis on in-depth interviewing and creating meaning from experience (Elliot, 2005). Given the limitations already discussed associated with narrative inquiry and storytelling, the research concept of reliability cannot be applied to narrative analysis. Elliot (2005) claims some authors argue internal validity is improved through the use of narrative, as the family member is empowered to set the agenda and the family member’s experience becomes less fragmented, with concrete and specific details about the research topic, by using their own vocabulary and understanding of the experience to describe the life event. This implies that the data obtained from narrative interviews are more accurate, truthful and trustworthy than structured interviews (Elliot, 2005). In addition, with the use of in-depth interviewing, the family member assumes
responsibility for creating meaning from the experience and the researcher can gain an understanding of the perspective of the family member. Other authors claim that the narratives told in research interviews are stories that are told in everyday life and in many contexts, blurring the distinction between the interview and real life and further increasing the validity of narrative (Elliot, 2005). However, it is rare for a person to have the opportunity to provide extended accounts of life experiences and the data collected are produced within the context of the research interview. A way of resolving this issue is dependant on the aims and objectives of the study. Researchers need to consider the topic to be addressed in the interview and the truth or insights we are seeking to understand. The questions should reflect these considerations. The aims and objectives should reflect the validity of the research process (Elliot, 2005).

With respect to external validity, narrative lends itself to small samples and the study results are only representative of the family members in the study (Overcash, 2004; Riessman, 1993), thus limiting the potential of the research to be applied in other settings (Overcash, 2004). Therefore, narrative lends itself to rich descriptions in different contexts. The reader is often left to determine the generalisability of the topic in similar settings or the common sense approach to generalisability (Elliot, 2005; Overcash, 2004). The generalisability of the study is dependant on the researcher being able to defend the trustworthiness of the study, the study’s strengths and limitations, and the extent to which the findings are relevant and applicable. Generalisablity can also be applied by the reader, who can isolate commonalities in the research data, which could be applied to similar persons in similar situations (Grinyer, 2007b; Overcash, 2004).

In conclusion, with regard to external validity or generalisability, Elliot (2005) summarises that narratives become the focus of research, not only because they provide an understanding of the meaning of the experience, but also because they provide us with the cultural framework for people to make sense out of their lives and as such “may produce evidence that is considered to provide an understanding of the intersubjective understanding shared by the whole community” (Elliot, 2005, p. 28). The external validity is determined by how widely the intersubjective meaning is shared by other members of the community and the boundaries of the community, who share this intersubjective meaning (Elliot, 2005).

Riessman (1993) suggests the validity of a narrative research study and in turn its trustworthiness can be approached by persuasiveness, correspondence, coherence and
pragmatic use. Persuasiveness relates to narratives supporting theoretical claims and providing alternative explanations of the data. It rests on the researcher’s ability to communicate, through writing the plausibility of the narratives. Correspondence involves member checks, ensuring the family members are involved in the research process, with family members responding to the researcher’s interpretation of the narrative, although, as Riessman (1993) states, “in the final analysis, the work is ours. We have to take responsibility for its truths” (p. 67).

Coherence involves the three levels of coherence identified by Agar and Hobbs (1982 as cited in Riessman, 1993): global, local and themal, with all three levels interrelated. Global coherence refers to what the family member is trying to achieve by the narration. Local coherence is the use of linguistic techniques to develop the narrative, whilst themal coherence involves content and attention to the development of certain themes in the narrative. This attention to the three levels of coherence offers a check on ad hoc theorising. The researcher continually modifies their interpretation of the narrative, as it relates to the person’s beliefs and goals, the structure of the narrative and the recurrent themes of the narrative. This results in interpretations, which are rich and related (Riessman, 1993). Pragmatic use involves the acceptance of the study by other researchers and whether the study becomes the basis of other work. This criterion is future orientated and cannot be validated in the initial study.

Not all scholars agree on the notion of validity within narrative research (Bruner, 1987; Mishler, 1986a, 1986b; Riessman, 1993; Sandelowski, 1991, 1993; Silverman, 2006). Further to this, Emden and Sandlowoski (1999 as cited in Taylor, 2006b) suggest a criterion of uncertainty, not as a methodological weakness, but as a criterion, which implies outcomes are uncertain and there may be no way of the study demonstrating otherwise.

In conclusion, in support of narrative method, Riessman (1993, p. 70) claims “our ultimate goal as a social scientist is to learn about substance, make theoretical claims through method, and learn about the general from the particular. Individual action and biography must be the starting point of analysis, not the end” (Riessman, 1993). In summary, she advises there are no standard rules, recipes, formulas or techniques for the validation of interpretative narrative studies.
DEMONSTRATION OF TRUSTWORTHINESS FOR THIS STUDY

As mentioned in the previous section, for the purpose of this study the trustworthiness, credibility, authenticity, and goodness of this research study are discussed within the context of Riessman’s (1993) suggestions to determine the trustworthiness of a narrative study. Although many criteria exist, I chose Riessman’s (1993) suggestions because of her longstanding expertise in narrative inquiry. Riessman (1993) suggests the following to make it possible for others to determine the trustworthiness of the study: “(a) describing how the interpretations were produced, (b) making visible what we did, (c) specifying how we accomplished successive transformations … and (d) making primary data available to other researchers” (Riessman, 1993, p. 68). She also suggests being transparent with our values and assumptions and not concealing them within the methodology of science. She provides no description of what these suggestions for trustworthiness mean, so I have interpreted the suggestions according to the previous discussion on the trustworthiness of a study.

Describing How the Interpretations Were Produced

The interpretations were produced by a narrative inquiry analysis method, as described in this chapter. This method was created from a selection of narrative inquiry and thematic analysis processes, within extant literature. In all cases, the various methods have been subjected to peer review scrutiny, thus it can be argued that they are trustworthy contributors to the overall narrative inquiry method I created within this research. This chapter also provides a detailed description of methods and process of how the family members were recruited, and how the interviews were conducted and transcribed for interpretation. The details will not be reiterated in this section, but they can be accessed in the completed thesis, stored at this University. Some details of these areas will also be published in refereed journal articles and disseminated at professional conferences. The process of member checking is also identified in this chapter.

Making Visible What I Did

The whole process of completing a PhD thesis involves making visible how I determined the way the study would unfold. The relevant chapters in this thesis all seek to demonstrate why this research is important. The thesis also provides ample
explanation for the justification of the methodology and research method most suitable for this study.

The study was also made visible to the family members within the research study, through member checking with the original transcripts and the emplotted core story being made available to the family members for verification and checking. Any changes suggested by the family members to their stories were incorporated and returned to the family members for further verification.

The beginning of this research study was closely supervised by my then supervisor Professor Bev Taylor, an expert in qualitative research methods. The trustworthiness of the study was discussed as making visible every step taken within the analysis to ensure a reader could comment on the integrity, credibility, authenticity and goodness of the study. Workshops were also conducted with my supervisor where the transcripts, the development of the core and emplotted stories and theme formation were cross-checked to ensure the authenticity of the analysis.

The Study is Visible and Accessible to Readers

A visible representation of how the analysis was conducted can be found in Appendix I. The representation demonstrates how the created story was sectioned through the use of subheadings. The cancer journey phases of the created story are also named within this visible representation. Therefore, the reader can observe how the subheadings and created story were used to create a plot or core story. Four emplotted narratives or core stories which provided in-depth rich descriptions of the experience for the family members in this study are presented in Chapter Five. In addition, reflections of the rest of the family members’ emplotted narratives or core stories are represented in this chapter. The emplotted core stories of these reflections are represented in Appendix J. From this representation the reader can identify how the themes were generated for the thematic analysis through the identification of the subheadings that provided the skeleton for the core stories.

If my thesis is recommended as satisfactory for the award of a PhD the completed thesis will be available from the Southern Cross University library thesis collection and through the Australian Digital Theses Program of which Southern Cross University is a member. The research process was visible to other researchers and postgraduate
students, with regular presentations at postgraduate seminars where my work in progress was made visible for comment and feedback.

**Specifying How I Accomplished Successive Transformations**

The narrative analysis method used in this study was an adapted hybrid combination of various authors’ approaches within narrative inquiry. The six steps identified for this method provided a logical connection to successfully analyse the stories to create meaningful representation of the family members’ stories and the collective themes associated with the stories. Step 1 Telling described in detail the interview method and how this is congruent with narrative inquiry. Step 2 utilised two authors within the field of narrative inquiry (Riessman, 1993 & Emden, 1998) and demonstrated the creation of the family members’ stories. This combination of methods identified the boundaries of the stories and how the stories related to the objectives of this study. Step 3 relied on Lieblich et al’s (1998) holistic content model to identify turning or transitional points with the created stories. This made it possible to look for themes that were specifically related to the transitional phases associated with the cancer journey in the created stories. Step 4 involved sectioning events in the created stories with the use of subheadings - a technique developed by Taylor (2006). This technique made it possible to identify themes and subthemes specific to the sectioned story and relevant subthemes. Step 5 involved narrative configuration or emplotting elements of the stories to create a core story which could be incorporated in this study. This enabled all of the family members’ stories to be honoured, which is important given the sensitive nature of the research study and the courage that the family members required to tell such a sensitive story. Finally, in Step 6, in order to create a meta-narrative or a collective analysis of the individual’s core stories, Taylor’s (2006) process of computer-assisted thematic analysis was utilised. Eventually, due to the large amount of data and the number of themes and subthemes, the NVivo8 software package was employed to continue with the analysis and to organise the themes. With the creation of these themes the study can provide some understanding of the collective experience of the family members, who have lost an AYA to cancer.

The narrative analysis method I created provided the necessary steps required to analyse data for this research study. The method made it possible to create the core stories and
to determine theme identification which related to the aims and objectives of this research study. The method suited the narrative style of inquiry, and added sufficient complexity to make it trustworthy.

**Making Primary Data Available to Other Researchers**

Making primary data available is difficult when ensuring confidentiality for the research family members. Although the family members in this study all requested that pseudonyms were not used, the primary data had identifying information with respect to other people and institutions within the story. This primary data could only be available to my supervisor as per my agreement to maintain confidentiality. When creating the core story identifying data were excluded from the working transcript. This de-identified data were available to my supervisors and other researchers and postgraduate students. The general direction of the stories and the emerging themes were shared and validated by my supervisor and at relevant research seminars.

This thesis demonstrates in Appendix I, one example using the primary (raw) pages of how the stories were formed. Furthermore, the collation and analysis of some of the primary raw data in this thesis will hopefully be published in peer reviewed journals.

In addition, the transcripts and the emplotted core stories which have been adjusted with no identifying information, except the family member’s and AYA’s name, will be available on request for five years after the publication of this research study.

**Being Transparent With My Values and Assumptions**

Values have been defined as principles or standards, “the accepted principles or standards of a person or a group” (Encarta Dictionary Microsoft office research). My values in relation to this study were motivated by my own story of being a mother, whose 17 year old son had died of cancer, and to try and create some meaning from the experience.
As Harold Kushner (1981) explains:

Let me suggest that the bad things that happen to us in our lives do not have a meaning when they happen to us. They do not happen for any good reason which may cause us to accept them willingly. But we can give them a meaning. We can redeem these tragedies from senselessness by imposing meaning on them. The question we should be asking is not, “Why did this happen to me? What did I do to deserve this?” as these are really unanswerable, pointless questions. A better question would be “Now that this has happened to me, what am I going to do about it?” (p. 182).

This study concerned what I was going to do about my own loss and to create some meaning out of what appears to be a cruel blow of fate. Because of my assumption of the isolation and the apparent lack of knowledge of the experience of young people and their families within the health system, I sought, through other families telling their stories to increase the understanding of this experience. I entered into the research process with a full understanding of my personal commitment to the study and the risk of being motivated by my own agenda. I was always mindful of this and regularly checked with my supervisor, other researchers and postgraduate students if my own subjectivity and position was influencing the research process. In addition, I have regularly referred in this chapter to how this may influence the research process. The reader is made cognisant of the ways I sought to address some of the issues that my own experience may have brought to the research process, within the ethics section of this chapter and the description of the interviews with the family members. The family members in the study were all aware of my story and the commonality of our experience. The impact this may have on the research process is also discussed in the ethics section of this chapter. The issues of the blurring of boundaries, which may have occurred because of my own story, are also discussed within the interview and ethics section of this chapter. As discussed in the limitations section of this chapter, I continually sought to be mindful of the influence my experience could have on the research process.

The other values I believe I brought to the research process involved my compassion and willingness to enable the person to tell their story of suffering through their own lens, and from their own interpretation of what the story meant for them. Therefore, I believe I brought integrity, honesty, compassion and empathy into this research process.
I facilitated the space for family members to tell the stories of love, courage, and sorrow from the beginning to the end. These were stories, which for many of the family members had never been told in-depth before. I also sought to engage the family members in the research process, through member checking, to ensure the family members’ stories maintain as much as possible the original meaning of the stories of suffering that were told. This highlighted the value I placed on the family members’ stories and the importance of the stories being represented according to the family members’ own world views.

Finally, as discussed within the section on limitations of narrative inquiry a preoccupation with the empirical can result in rigour being an unyielding end in itself rather than an understanding of narrative truth (Sandelowski, 1991). As Sandelowski (1993) has argued, if we impose strict criteria to narrative analysis we may succumb to technique rather than perfecting the craft with rigour becoming an end in itself. Therefore, whilst I have provided some explanation on the trustworthiness of this study, it is wise to reflect that within narrative inquiry the researcher is interested in the interpretation of the meaning, not the truth, from the stories that family members tell.

CONCLUSION

This chapter provided an explanation of the methods and processes used to analyse and create meaning from the family members’ stories. Narrative was the methodology of choice, as the stories are stories of suffering comparable to the illness narratives described by Kleinman (1988), Frank (1997) and Hyden (1997) and Sakalys (2003). The illness narrative supports the use of open-ended questions and the emotionalist model of qualitative research. The illness narrative also lends itself to a shared understanding of the suffering to create meaning from the stories. The authors whose guidelines influenced the method developed for this study included Mishler (1986a, 1986b), Riessman (1993, 2004a) with the emphasis on the open-ended interview, Riessman (1993), Emden (1998b), Polkinghorne (1995) (1998), Lieblich et al (1998), and Taylor (2006), who provided guidance on the interview, creation of the core story, identification of transitional phases, sectioning of the core story, configuration of the story and computer-assisted thematic analysis. In addition, the limitations of the study were explored and the steps taken to ensure the trustworthiness of the study examined.
The next three chapters present the analysis and interpretation of the family members’ stories. Chapter five contains four exemplar core stories. Chapter six contains the meta-narrative of the family members’ stories within the departure, exploration and anticipation stage of the cancer journey. And chapter seven contains the meta-narrative of the family members’ stories within the destination stage of the cancer journey.
CHAPTER FIVE: ANALYSIS AND INTERPRETATION

CORE STORIES AND REFLECTION ON CORE STORIES:

DEPARTURE, EXPLORATION, ANTICIPATION AND DESTINATION

Telling the stories.

“We can tell people abstract rules of thumb which we have derived from prior experiences, but it is very difficult for other people to learn from these. We have difficulty remembering such abstractions, but we can more easily remember a good story. Stories give life to past experience. Stories make the events in memory memorable to others and to ourselves. This is one of the reasons why people like to tell stories.”

Roger C. Shank, from Tell Me A Story (http://www.storyteller.net/articles/160)

INTRODUCTION

This chapter in the main presents four core stories of family members whose AYA was treated for and eventually died of cancer. As discussed in chapter four the core stories were configured and emplotted using a combination of the following theorists narrative analytical methods Taylor, (2006) Riessman, (1995) Emden, (1998) and Polkinghorne (1988,1995). Using these methods the family members’ transcripts were emplotted and configured to produce a core story with a beginning a middle and an end. As such the stories are a summary of the events in temporal order within the identified transition stages or turning points of the cancer journey, Departure, Exploration, Anticipation and Destination. The events selected addressed the research aims and objectives of this study. The core stories refer to events in which one AYA died over twenty years ago and those whose family member died only twelve months previously. From the core stories, commonalities and differences of the events can be identified. This assists in the thematic analysis, and the resultant configuration of the meta-narrative, described in the previous chapter, and presented in Chapters Six and Seven of this study.
Theses core stories provided rich and in depth descriptions of the experiences of family members who have lived with and lost an AYA to cancer. Given the depth and length of the 23 core stories which were created it was decided to use only four of these core stories as exemplars. The four examplar stories are from Deborah, mother of Matthew Anthony, (paediatric system of care); Jenny, mother of Brenton Duncan, (paediatric and adult system of care); Fulvia mother of Jadye; and Helen and Geoff, father and mother of Mick (adult system of care). The stories of Helen and Geoff, although told separately, were combined because of their common narrative. The remaining 19 core stories can be found in Appendix J.

This chapter also represents my reflections of the 19 core stories of the other family members in this study. This is done to give the reader a broader understanding of all the stories in this study without having to mine through the enormous quantum of data that was generated in the core stories. These stories are from: Cameron, brother of Kristie; Irene, grandmother of Thomas; Mike, grandfather of Thomas; Josephine, mother of Christopher, (paediatric system); Kerry mother of Alinta; Pam, mother of Tamina; Val, mother of Anthony Charles and Susie; Tania, sister of Anthony Charles and Susie; (paediatric and adult system of care); Denise mother of Brenton James; Cathie and Heather sister and mother of Paul Vincent; Trish and Heather, sister and mother of Paul Vincent; (Cathie and Trish told their stories in two separate interviews with their mother Heather being present in both); Alan, Marilyn and Rebekah, father, mother and sister of Naomi; Arlene, mother of Mathew James; Sue, mother of Ben; Lauren, sister of Grant; Shane and Andrea, father and step-mother of Grant; and Cheryl, mother of Paul Malcom (adult system of care).

The core stories and reflections come from the experiences of these families in the paediatric system, and both the paediatric and adult system and the adult only system of care. The core story and the reflections of the core stories are presented in the order of these systems of care. (See Table 5.1)
### Table 5.1 Storyteller’s Relationship to AYA and System of Care

<table>
<thead>
<tr>
<th>Family member</th>
<th>Relationship of Family member to AYA</th>
<th>AYA Name</th>
<th>System of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deborah (core story)</td>
<td>Mother</td>
<td>Matthew Anthony</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Cameron</td>
<td>Brother</td>
<td>Kristie</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Irene</td>
<td>Grandmother</td>
<td>Thomas</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Mike</td>
<td>Grandfather</td>
<td>Thomas</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Josephine</td>
<td>Mother</td>
<td>Christopher</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Jenny (core story)</td>
<td>Mother</td>
<td>Brenton Duncan</td>
<td>Paediatric and adult</td>
</tr>
<tr>
<td>Kerry</td>
<td>Mother</td>
<td>Alinta</td>
<td>Paediatric adult</td>
</tr>
<tr>
<td>Pam</td>
<td>Mother</td>
<td>Tamina</td>
<td>Paediatric adult</td>
</tr>
<tr>
<td>Val</td>
<td>Mother</td>
<td>Anthony Charles</td>
<td>Adult</td>
</tr>
<tr>
<td>Val</td>
<td>Mother</td>
<td>Susie</td>
<td>Paediatric</td>
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<tr>
<td>Tania</td>
<td>Sister</td>
<td>Anthony Charles</td>
<td>Adult</td>
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<tr>
<td>Tania</td>
<td>Sister</td>
<td>Susie</td>
<td>Paediatric</td>
</tr>
<tr>
<td>Fulvia (core story)</td>
<td>Mother</td>
<td>Jadye</td>
<td>Adult</td>
</tr>
<tr>
<td>Geoff (core story)</td>
<td>Father</td>
<td>Mick</td>
<td>Adult</td>
</tr>
<tr>
<td>Helen (core story)</td>
<td>Mother</td>
<td>Mick</td>
<td>Adult</td>
</tr>
<tr>
<td>Denise</td>
<td>Mother</td>
<td>Brenton James</td>
<td>Adult</td>
</tr>
<tr>
<td>Heather</td>
<td>Mother</td>
<td>Paul Vincent</td>
<td>Adult</td>
</tr>
<tr>
<td>Cathie</td>
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<td>Paul Vincent</td>
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<tr>
<td>Trish</td>
<td>Sister</td>
<td>Paul Vincent</td>
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<tr>
<td>Alan</td>
<td>Father</td>
<td>Naomi</td>
<td>Adult</td>
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<tr>
<td>Marilyn</td>
<td>Mother</td>
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<tr>
<td>Rebekah</td>
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<td>Arlene</td>
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<td>Mathew James</td>
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<td>Lauren</td>
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<tr>
<td>Shane</td>
<td>Father</td>
<td>Grant</td>
<td>Adult</td>
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<tr>
<td>Andrea</td>
<td>Step mother</td>
<td>Grant</td>
<td>Adult</td>
</tr>
<tr>
<td>Cheryl</td>
<td>Mother</td>
<td>Paul Malcolm</td>
<td>Adult</td>
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</tbody>
</table>

For the purpose of this study the core stories and the reflections are sequentially organised according to the system in which the AYA received care.
Core Story of Deborah - Mother of Matthew Anthony

DEPARTURE

I first noticed something was wrong when I became aware of a lump on Matthew Anthony’s thigh when he was 12 years old. I remember him having a CT scan and ultrasound and being referred to a surgeon. The surgeon thought the lump was pretty safe although he said it would need to come out. It took a week after the surgery for the results to come back and I had a gut feeling that something was terribly wrong. When the surgeon asked me to come in I said he might as well have told me over the phone as it was pretty obvious. When Matthew Anthony and I were told, the doctor was really good. We were provided with pamphlets and contact numbers for Matthew Anthony. We had to go to the Children’s Hospital in Melbourne the next morning and having to organise my other children was difficult. They had told me that they didn’t know how long we would be staying so I packed quite a bit.

The doctors didn’t say much to me just that it was a rare cancer. I felt angry that he couldn’t have got a common cancer. He had all these tests, bone scans, MRIs and CT scans and surgery to put his porta cath in, to start chemotherapy. The doctors sat us down and told us he’d be lucky to survive the cancer but they would give it their best shot.

EXPLORATION

Matthew Anthony had ten months of chemotherapy every two and a half weeks. During this time I had to leave my two other children with my mother which was really difficult on her. He had complications with his kidneys from the chemotherapy. After ten months of chemotherapy they told us that they could do no more. The cancer appeared to be gone. Although, the oncologist said it was not a matter of if it comes back, but when it comes back.

Initially I believed everything the doctors said until someone said to me, this is your child you have every right to question everything they are doing. So I did
and I found they didn’t like being questioned. I recall asking a doctor what lymphatic and blood vessel invasion meant which I had read on Matthew Anthony’s discharge sheet. The doctor said that people like me with no medical background should not be reading things like this. I was very confused with the doctor’s answer. The doctor said it doesn’t mean anything, it just means he has cancer in his lymph nodes and his blood and that it is everywhere. I knew it was in his leg and his lungs but I didn’t know it was everywhere else. The doctor then said, it’s not everywhere else, this confused the hell out of me. In the end I would not see this doctor because I felt she was rude and there was no compassion. I spent a lot of time being quite angry with her. Although I thought she must have grown a heart because she delivered the news so well that he only had a couple of weeks to go when he had been told he was terminal. I thought eventually that I was right all along about this doctor when the doctor said that it was ridiculous that Matthew Anthony wanted to go home to die if he only had a couple of weeks.

I didn’t want counselling, that was time when I could have been sitting with Matthew Anthony. There was one occasion when a social worker asked me to have a chat with her. The social worker had already seen Matthew Anthony’s father and there was a lot of tension between us at the time. I felt this social worker was incredibly nasty and rude to me. I actually wrote a letter of complaint but never ended up sending it. The social worker was terrible.

The nurses were really good although busy, short staffed and run off their feet. I and the other parents would not buzz a nurse if our children had vomited or used a bottle. We would leave the bottle or the bowl in the pan room with the name and time on a piece of paper and get a fresh one. I recall that on a couple of occasions I thought the nurses could do with a bit more sympathy towards the children. I could hear them at the nurses’ station when you walked past saying, “oh god I wish that kid would stop crying.” The crying was driving us all crazy and nobody wants to listen to a kid crying all the time but when you looked at the reasons why it was heartbreaking more than annoying.

During his treatment it was OK in the Children’s oncology ward because they all had their own TV and video and there were lots of PlayStations, Nintendos and laptop computers that they could take to their bedside. I felt safe and confident
with the nursing staff on the oncology ward because they knew what they were doing. There were times when Matthew Anthony had to be admitted to other parts of the hospital and I felt stressed because the nurses weren’t familiar with kids and chemo and I had a lack of confidence. Despite the massive amount of information before long I knew his exact chemo routine. I found it difficult to leave him at night and wondered who was going to stick up for him if something goes wrong. I recall one incident where two nurses insisted that one of his chemo drugs was to be administered over 20 minutes instead of two hours. I insisted they get a doctor to confirm it and the nurses apologised because it was to be administered over two hours. I remember after that I watched everything they did because mistakes can happen and I wasn’t going to let any happen to Matthew Anthony.

I told Matthew Anthony to get the nurses to call me if he needed me at night and I would come. One night he had a bad night and woke up crying and wanted the nurse to ring me. The nurse told him not to be ridiculous and that his mum needed her rest. When I found out the next morning I was wild. I would have come in and held his hand and gave him a cuddle because that is what mums do. He was 12 and he still needed his mum. Even at 17 and 18 he still needed his mum. I believe that because he was older they expected him to be more mature than the other kids.

He had a bone marrow biopsy and I mentioned to the doctor that a friend had told me to knock him out because it was painful. The doctor said they knock the little ones out but he was 12 and a big boy. They gave him Midazolam and a local anaesthetic and it didn’t touch him. It took five of them to hold him down and he remembered every bit of it. I remember Matthew Anthony being assertive with the doctor and saying if he ever did another bone marrow biopsy he was to put him to sleep and for the doctor to sign and put it on paper that he was going to give him a general anaesthetic.

He had to have a gamma globulin injection at the local hospital because he had been exposed to chickenpox. The Children’s Hospital had sent the stuff down and I had to pick it up from the train station at 9pm and take it to Casualty. We were finally seen at 12am but they didn’t know what to do, so they had to ring the hospital in Melbourne. He finally got his injection at 4 am in the morning.
After they gave him the injection he couldn’t walk because they had given him the whole lot on one side of his bottom and it is a big needle that had a big volume. I think it was 50 mls or something. The next time he needed gamma globulin I drove down to Melbourne and it was quicker.

The cancer treatment affected the rest of the family. His younger brother was three at the time and didn’t like being away from me. My daughter, who was ten at the time, got a little neglected. I was so absorbed in Matthew Anthony and I’ve had terrible, terrible feelings of guilt over that. It was difficult for my mum, who cared for the children when I was in Melbourne. My younger sister, who was studying for Year Twelve at the time, had to have these two noisy kids around all the time which affected her schooling. It just threw everybody’s life out of whack. The financial side was also really tough.

Despite all this Matthew Anthony was the family’s strength. He brightened the room up even when he was really sick. He had a real sense of humour and it was very hard to be miserable around him. He would love to get out even for ten minutes on his bike or skateboard. I thought he might be pushing himself too hard and going to make himself worse. I remember him spending a whole day on the beach with his boogie board. I was worried about him because he was getting really tired but he told me, “no Mum, I’m having fun.” It took him two weeks to get over it.

Eventually, I stopped putting my foot down. I was thinking he has cancer he could die and he should be allowed to take risks. After that Matthew Anthony and I would sit and talk about things and we had a very open relationship.

I felt guilty as when he was first diagnosed the doctors had told me not to tell him the full extent of what was going wrong and also not to cry in front of him. Matthew Anthony was not stupid; he knew that I was keeping a secret from him. He told me he had a right to know what was wrong with his body so I sat down with him and told him everything and he took it really, really well. He made me promise there would be no more secrets. The next time the doctor wanted to talk to me in private I said to him, anything you say can be said in front of Matthew Anthony. The doctor wasn’t real keen but Matthew Anthony said, “it’s my body, it’s my life so I have right to know.”
I realised that it was OK to have a cry together and to talk about the cancer because I couldn’t pretend it wasn’t there and we couldn’t make it go away. I don’t know how it happened but we just got right in and talked about everything. We had open discussions about death; these became more open when he got sick the second time.

**ANTICIPATION**

In between his first and second lot of treatment there was a lot of emotional stuff and doctors weren’t that interested. After the first lot of treatment I fell in a heap. When Matthew Anthony was 16 he developed a teenage attitude to school and home. He actually took an overdose. He’d missed a lot of school with his first lot of chemo and was always a bit behind the eight ball. He decided he didn’t want to go to school and he hated life, so he quit school. I tried to convince him to get a job or go to TAFE. I was always a little soft on Matthew Anthony because of what he had had to go through and it wasn’t his fault that this had happened to muck everything up. He spent about ten months doing nothing and he became really bored and I could see his mood slipping. I kept taking him back to the doctor and saying he needed something. They kept saying he’s just a normal kid whose had a little bit extra to go through and it is just a phase he is going through. They said he didn’t need tablets or counselling and it felt like no one was helping. When he did get counselling they focused on him wanting his parents back together. This could have been part of it, but it wasn’t all of it. The local counsellors weren’t exposed to a young person with cancer, and really didn’t know how to deal with it.

Over the six years that Matthew Anthony was sick I had too many bad experiences with the local services and would now go to Melbourne for anything major. Matthew Anthony ended up taking an overdose and having a drug induced psychosis, he went absolutely berserk, the look in his eyes was like that of a wild animal. He threatened to kill me but I knew he wouldn’t. He escaped from the hospital and the police got him. I don’t know what they did to him but he had to be bandaged for quite some time and he was terribly bruised and battered. The week in the Psychiatric Hospital was the best thing that ever happened to him because somebody listened and he got the help he needed.
About two months after that, the sadness had gone and he was doing really, really well. He had said he was going to be an electrician and went back to complete Year 10. The mid year report was the best secondary school report he had ever had, he got As. It was a lot of hard work, with family counselling sessions, particularly with me and Matthew Anthony. I had a glimpse of the kind of man that Matthew Anthony would become. Then everything fell apart.

**DESTINATION**

He had regular checkups and was becoming a little blasé because his checkups just kept getting better and better. Then, when he was seventeen he complained of a pain in his testicles. Initially, they thought it was a twisted testicle. They called the surgeon in and he pulled me aside and said it was not good as he had a large lump in his stomach and pelvic area.

Matthew Anthony and I returned to Melbourne where they gave him two lots of chemo, but the tumour was still growing and resistant to the chemo. They then told us he was terminal.

Matthew Anthony had wanted to freeze his sperm just in case the next lot of chemo was the one that determined he couldn’t have children. I mentioned it to the doctor, who said “it was the most ridiculous thing she had ever heard.” Matthew Anthony said he wanted it done and the doctor was saying, “we are an oncology department not a sperm bank so it is not going to happen.” This doctor was a horrible woman and just shot him down in flames. Matthew Anthony decided not to freeze his sperm when he found out he was terminal.

Matthew Anthony made a few connections with the nurses the second time he was sick. I think it was because he was older; they would sit and talk to him, particularly on night duty if it was quiet. One nurse was a local girl who came to his funeral, which was nice.

He found it really hard in the Children’s Hospital the second time around. One time he was in a ward with all these little kids and they were all watching Thomas the Tank Engine and High 5 and crying and he was almost a man. He was too big.
Matthew Anthony had said that if the cancer came back he did not want chemo but I had this hope in the back of my mind that if it did come back his will to live would shine through. His will to live did shine through because when it came back he said, “when do I start chemo?” He fought it even though there really wasn’t any point. It wasn’t until he gave up the fight and resigned himself to the fact that he wasn’t going to get any better that things started to go wrong. We had been told the tumour was inoperable and as it grew it would start pressing on his internal organs. About six months after he was told it was terminal the tumour blocked the urethra and he had to have a stent put in. I believe this is when he knew he was not getting any better and what the doctors said was going to happen was happening. He just gave up after that and it was all downhill from there on. Up until that time he was just very tired but physically he was OK. He said to the doctors he didn’t want to keep coming to Melbourne, that he was sick of it and he wanted to be home with his family and friends. The doctors in Melbourne wanted to keep seeing him and Matthew Anthony just point blank refused to go. The local paediatrician supported him and got on to the doctor in Melbourne and said Matthew Anthony doesn’t want to go back, that they had told him he was terminal and he wants to stay home where he has his family and friends.

We had to return to Melbourne a month before he died to manage the pain in the sciatic nerve. He had foot drop and was having trouble walking. It was painful but while he could still walk there was no putting him in a wheel chair. They put in a temporary nerve block and once they got it right they were going to put a permanent nerve block in but something went wrong. While he was in Melbourne he had an internal bleed and his haemoglobin was really low, the doctor said they could give him a blood transfusion which may give him an extra two weeks. I remember Matthew Anthony saying “how much time do I have?” and the doctor saying, “I don’t know but it is soon.” Matthew Anthony said he wanted to go home and he didn’t want to die in hospital. The doctor told him he couldn’t go home. I was fairly emotional I got really really crusty with them and said “we’re going home.” They weren’t happy about it but gave in and ended up organising an air ambulance to fly him home.
When we got home the ambulance men that picked us up from the airport were really great once they found out what was wrong with him. We settled him into the hospital bed in the lounge room because he had felt isolated in his bedroom. This was difficult because he couldn’t walk but he could support himself on one leg. I remember taking him out in his wheelchair for smokes. He couldn’t eat or drink at this stage. I eventually made the decision that he could smoke inside because it got to the point where he was just too exhausted to smoke outside. I spoke with him about the District nurses coming to wash him as he was a man and I was not sure I felt comfortable washing him, but he told me he didn’t want a stranger looking after him. My whole day was pretty much taken up with his needs and I gave up work to care for him.

The District nurses were absolutely fantastic, they were there for the whole family.

I started having panic attacks three weeks before he passed away. When I had my first attack I didn’t know what was happening and the District Nurse turned up and talked me through it. Afterwards we talked about me wanting him to see a priest and the nurse organised the priest to come and see us the next day. I felt much better after the priest’s visit; he anointed Matthew Anthony and was able to answer some of Matthew Anthony’s spiritual questions.

He got a bowel obstruction the Sunday before he died and he was vomiting constantly what looked like poo. They put a nasogastric tube down which drained the stuff he was vomiting. He was on a lot of morphine at this stage which pretty much kept him out of it. We never really managed his pain and a few times I had to leave the room when the doctor was doing something because he was screaming in agony. I feel I may have coped better if his pain had been managed. I recall Matthew Anthony asking, “why am I suffering like this?” He said, “if I was a dog they would have put me down months ago.” He actually asked me to kill him and I said I couldn’t do it because it was against the law. I remember having a personal battle with myself about what I should do. I eventually spoke to the doctor about doing something to make him more comfortable or I would kill him, as that is what Matthew Anthony wanted and as his mother I had to look after him. The doctor organised a syringe driver so he
had constant morphine going in which zonked him out, but when he was awake
he was still in pain.

Despite this in the last month there was an incredible amount of bonding. I
remember watching the beautiful relationship develop between him and his
sister. The last month everything was all about Matthew Anthony, nothing else
mattered we all just wanted the best for him.

Two hours before he passed I leaned over him to top up his morphine and he
said, “I’m very close I’m going to die soon aren’t I?” I said, “yes, I think so.” The
last thing he ever said was, “good.”

When he died we were all sitting around him and one of Matthew Anthony’s
CDs was on as background music. It was a beautiful experience, sad and hard,
but beautiful at the same time. When he took his last breath he sat bolt upright,
his arms stretched up in the air and he focused on a particular spot even though
he couldn’t see. I felt this was a real spiritual thing. When he died I lay on the
bed with him and cuddled him for hours. I needed to do this because I had not
been able to really cuddle him because it hurt him so much.

I felt guilty after he died because I felt relieved that his suffering was over. He is
no longer suffering and our suffering has really only just begun. We are
unhappy because we miss him but we are not unhappy because his suffering is
over. I keep reminding myself that for him to not suffer anymore he has to not
be here and that helps. I knew it would have been selfish to try and keep him for
longer because we didn’t want to lose him. It was about Matthew Anthony and
what was best for him. Because it was all about Matthew Anthony as a family
we bonded and united so much.

He had told me that after he died he would turn the power off in the house for a
minute at 8. 00 clock that night. When his body was still in the house the power
went off for a minute. I thought it was unbelievable.

After he died I took his clothes to the funeral home and the funeral director
suggested that I dress him. I dressed him and put two pairs of socks on him and
wrapped him in a blanket so he wouldn’t feel cold and it made me feel better
that I had rugged him up so he was nice and warm. I was glad I did it even though technically he couldn’t feel the cold because he was dead.

**Reflections of Core Stories in the Paediatric System**

Deborah’s core story is an exemplar of the experience for family members where the AYA was cared for in the paediatric system. What follows next are summaries of the remaining core stories of those cared for in the paediatric system. These summaries are reflections of themes and issues within the core stories. The core stories of Cameron, Irene, Mike, and Josephine can be found in Appendix J.

**Reflections of Cameron’s Story - Brother of Kristie**

Cameron was able to articulate how the cancer interfered with his sister’s sense of self and development. He discussed how the cancer became a part of the family life. The implication of this was the burden it placed on the family, such as the travelling for Kristie to receive her chemo and his mother having to give up work to care for Kristie. He always saw himself as Kristie’s big brother and he was there to care for her during the journey. He spoke of the roller coaster ride of treatment hitting rock bottom and having to start all over again. During all this Kristie sought to be as normal as possible, attending school and schoolies (a gathering of school leavers, usually at a holiday destination, celebrating the end of their school life) a month before she died. Similar to Deborah’s story about Matthew Anthony and his sister, Cameron felt a deep bonding with Kristie before she died augmented with Kristie’s expression of love towards him. As with other stories Cameron felt relief when she died because she was free.

**Reflections of Irene’s Story - Grandmother of Thomas**

Irene’s initiation into the cancer journey was initially with some confusion at being unaware if a tumour was cancer. Irene’s core story speaks of her admiration for her grandson’s courage and resilience as he progressed through
the stages of the cancer journey. She was particularly impressed with the way he handled his amputation. She knew that Thomas did not like hospitals but also acknowledged that that was the best place for him when he was having treatment. Her main concern was watching children suffer, the lack of privacy for Thomas in addition to Thomas being surrounded by crying babies. She spoke of Thomas’s courage and how amazing he was in the way he accommodated his amputation. Thomas travelled the Destination stage of the cancer journey at home. Irene found this helpful as they could make the environment as comfortable as possible for him and accommodate his friends and family. She believed that given the choice, dying at home is the best place for young people. When Thomas reached his final destination Irene found it hard that she could not say goodbye. She expressed how amazing Thomas’ friends were when they lifted his dead body onto the undertaker’s trolley. It was important to her that she had some time with his body after death and to cuddle and kiss him before his body was taken away.

Reflections of Mike’s Story - Grandfather of Thomas

Mike knew there was something serious when Thomas was first diagnosed. Initially when Thomas was having chemotherapy he thought he would be alright. It was only after Thomas had an amputation that he realised he might die. Mike found it difficult being at the hospital as though he was climbing up a ladder and not knowing what to expect and what questions to ask. He knew Thomas was going to die when he asked a doctor. He found it difficult watching a young man slip away like that. Mike also commented that he found it hard losing all his friends when Thomas was travelling the cancer journey. Mike commented that because he was a man he didn’t believe he needed counselling.

Reflections of Josephine’s Story - Mother of Christopher

Josephine speaks frankly about the harrowing journey that she and Christopher embarked on after his diagnosis of Ewing’s sarcoma. Her story tells of how, on many occasions, she was required to be a strong advocate for Christopher in order for him to receive the treatment he deserved and to facilitate her being able to continue her role as a single mother with three other children. She spoke of problems with communication with the health care providers and how she
was mostly dependent on other parents to understand and deal with the horrible side effects of treatment.

She was unprepared for these side effects and constantly struggled with what to do. She spoke of the initial experience of the adult system tumour ward that influenced her decision for Christopher to be cared for in the paediatric system. Her descriptions of the adult system and the paediatric system highlighted that the paediatric system catered more for Christopher’s needs and stage of development; the adult system environment being aesthetically unpleasant and Christopher being surrounded by old men. Christopher demonstrated remarkable courage by organising his own funeral. She found the dying hard as she was a single mother and just wanted it to end so she could care for her other children. She spoke of how tired she was. When he did die she realised that you are never prepared for this. To assist with saying goodbye she bathed him and the next day dressed him in the clothes in which he had requested he be cremated.

TRANSITIONS FROM PAEDIATRIC TO ADULT SYSTEMS OF CARE

Jenny’s Core Story - Mother of Brenton Duncan

DEPARTURE

Brenton Duncan was told he had three months to live, but he lived two years longer than expected. When the cancer returned 18 months later, in the year 2000, I realised that Brenton Duncan was older and more aware of what was happening to him. After an MRI, Brenton Duncan was re-diagnosed with a re-occurrence of the cancer in his leg. When the cancer reoccurred they did not know what treatment to give him because it was such a rare cancer. He had to return to the Children’s Hospital where he had been when he was 12 but now he was a teenager. There did not seem to be many teenagers diagnosed with cancer in the Children’s Hospital and because of this there was no one his age he could bounce off or talk to about what he was going through. They did have a ward for teenagers but it was not for cancer patients.

EXPLORATION
Brenton Duncan started on a drug trial. It was the worst chemotherapy I had seen, he was bleeding from the bottom and every part of him, it burnt everything and he was sick. He was always neutropenic and because of this he was cared for in a back private room where they normally do stem cell infusion. He was in hospital for several months and I stayed at Ronald McDonald House during this time. I was a single mum and I got through this time with the help of my girlfriend.

After the chemotherapy I was told Brenton Duncan was probably going to die. I had read about microwave therapy in Perth and Brenton Duncan knew of a girl who had metastasis who had the microwave therapy and it cleared up the cancer. So, we raised $5,000 and went to Perth for the therapy. The therapy didn’t work, although a metastasis in his shoulder did disappear. We returned to the Children’s Hospital as there was nowhere else to go.

He had to have radiotherapy at Peter MacCallum in Melbourne to keep the cancer under control. The waiting room was full of old people in wheelchairs and there was only one other teenage girl, who later died. I thought this was awful, to expose a 16 year old to all these 80 year olds. The staff appeared to understand this but there was nowhere for him to go and there was nothing for him to enjoy in that environment. He just had to join in with the old people and wait his turn. Brenton Duncan would say: “Mum, why me? Why, it’s not fair mum, what have I done wrong to get cancer at my age instead of being old?” This made me very, very sad and it was hard.

When he got the metastasis it was hard for Brenton Duncan being virtually a man and being surrounded by little kids and babies when he was dying of cancer and had no one his age to talk to. I knew everything about Brenton Duncan and it was difficult at times to be Brenton Duncan’s sounding board. He spoke to me about dying, his fears, and the way he felt and his sex life as he had no-one else to really talk to.

I realised that there were no facilities for teenagers with cancer, no support system or ward for them. His stay in the Children’s Hospital and having radiotherapy at Peter MacCallum were both problematic and I believed there should be some sort of cancer facility which catered for all the treatment of
cancer for teenagers, because they don’t fit in as a child and they don’t fit in as an older person.

After the radiation therapy we pulled away from the hospital to look for other solutions. But, we had to return to the hospital for more chemotherapy that was then stopped because he started to bleed from the kidneys. After this, they decided to amputate his leg, as there was a big tumour growing behind his leg again and the tests appeared to show there were no metastases.

When he returned to the Children’s Hospital this time, he was a full on teenager, virtually a man and grown up. He was nearly 6 foot tall and the oldest in the ward. He was shaving, ready to start part-time work, and having sex with his girlfriend. I just felt for him as there was no one his age to talk to him like a teenager. It was so undignified for him to be back in the Children’s Hospital, having to go through what he went through and not be a person in his own right, surrounded by little kids and babies crying in the night.

The Children’s Hospital did try to make his stay easier, he had his own room and his friends would come and cheer him up and his girlfriend was allowed to sleep in his room at night. The nurses loved Brenton Duncan and were very good about that.

When Brenton Duncan returned home after the amputation he was optimistic for the future, he said he was cancer free and life was going to be good. But, seven weeks later I sensed that he was not getting better. I contacted the Hospital who told me to bring him in for tests. The radiologist showed me a big tumour in his groin that was painful. I later found out that the cancer was everywhere.

**DESTINATION**

When we went home from the Children’s Hospital I was rung at work and told Brenton Duncan was going to die, that he had metastasis everywhere. That night I told Brenton Duncan it had come back but I thought Brenton Duncan already knew he was going to die. He cried and then told me he would be okay and not to worry about him. He continued his relationship with his girlfriend and I gave up work to be with him.
One day when Brenton Duncan was at his girlfriend’s I was rung to say Brenton Duncan was in absolute agony. I went to see him and he was lying on the floor screaming in agony, wanting something to knock him out for the pain. The pain had come on suddenly as he had been fine that morning. I got the district nurse to come and give him some morphine. He had a driver put in and he was brought back to my house and put into bed so I could look after him. After this the palliative care team from the Children's Hospital came to tell me what to expect.

I don’t feel I got any real support from the Children’s Hospital when he was dying. One night when I couldn’t cope, we got an ambulance to the Children’s Hospital and I asked for him to be admitted. The Hospital said they could not do anything for him as he was dying. I asked, “where else can I go?” They suggested the hospice around the corner but it was full of old people and I couldn’t put Brenton Duncan there.

I knew he wanted to die at home but it was really hard doing it all by myself and with my girlfriend. There was no support, the district nurses were all different and there was no constant support person. I talked to the Children’s Hospital about this lack of respite and support. I would have liked the Hospital to provide a nurse who had known Brenton Duncan through his time in hospital to provide care at home. I even said I would pay for the nurse but it could not happen.

I felt concern that I had complete control over my son and worried that I could kill him and overdose him on morphine, but there was nobody else there to look after him. It was an awful time and I wanted structured, organised help, someone who could coordinate Brenton Duncan’s care.

During this time I heard Brenton Duncan beg his GP to die because he was in so much agony. As it went on he became so sick, he was falling over because of the drugs, he couldn’t do things for himself, he needed to be shaved, he drank out of a baby’s bottle because he couldn’t feed himself and in the last two weeks he just lay in bed. I found it really, really hard work and would have liked some respite every so often. He was still able to have conversations with me towards the end, which was nice.
Despite all the hard work, he made his death easy for me as he was always thinking of other people and giving out to them. For example, he was so concerned for his girlfriend and he thanked the Professor for looking after him when he told him he was going to die.

The day he died I asked the district nurse if he would die that day as he had the death rattle. The nurses said he could go on for another week because he was so strong and that he probably wouldn’t die that day. That day my girlfriend Chris, my future daughter-in-law Bec, and Todd, my youngest son, were all there, but we didn’t know he would die. We went to turn him. We turned him, he was groaning and I was cuddling him when all of a sudden he reached up and then lay back down and died in my arms. It was lovely and I felt lucky that he died in my arms.

**Reflections of Core Stories in Both Systems of Care**

Jenny’s core story is an exemplar of the experience of family members where an AYA is cared for in both system of care. What follows, as with the paediatric system of care, are summaries of the remaining core stories of those cared for in both systems. The family members experienced both systems of care as a result of a transition from the paediatric to the adult system, as with Jenny and Pam, or as with Kerry as a result of there being no other alternative system of care. Val and Tania were included in both systems of care as they experienced the adult system of care for Anthony Charles and the paediatric system for Susie. As with the paediatric system of care these summaries are reflections of the themes and issues within the core stories. These core stories can also be found in Appendix J

**Reflections of Kerry’s Story - Mother of Alinta**

Kerry’s story highlights the plight of a single mother trying to provide the care that Alinta requires as she is dying. Much of Kerry’s story speaks of lack of information and support, being isolated and dislocated, and the difficulties of being a single mother whilst your child is dying of cancer. With the initial diagnosis Kerry found the information she was given, and the way she was
given it, difficult. For example, like Irene she was unaware that a brain tumour could be cancer. Her initiation into the cancer journey was her daughter being airlifted to Brisbane via helicopter and Kerry travelling the 200kms on her own, the whole time being afraid that Alinta might die.

From this initial situation Kerry found it difficult to negotiate the cancer landscape believing the information she was given was difficult for her to assimilate and understand. This resulted in her feeling she did not have enough information to make the correct decisions for her family. During this time she found it difficult to access things in order for her to fulfill her role as a single mother. She recalled there was no plan as to what she was supposed to do. Added to this was having to witness the horrendous consequence of the cancer treatment, such as being prepared for radiation and the horror movie of seeing Alinta after her operation.

Kerry felt so isolated she thought she may as well be on Mars. When she was told Alinta was going to die she was terrified because she had never seen anyone die and didn’t know what to expect. This isolation was evident when Kerry cared for Alinta at home when Alinta was dying. From the story there appeared to be little support, with her commenting that people tend to stay away from you. She was required to give up her job in order to care for Alinta. Added to this was her position as a single mother and she found it difficult to manage as a single mother, with no money, who still wished her children to experience what other children experienced.

She commented on the burden to her children, as they had to take on other roles as a result of the cancer journey. She found caring for Alinta at home hard and, like Jenny, would have appreciated someone who would coordinate the care. She was not aware of simple things that may have made the journey easier such as being able to park in a disabled parking spot; her comment being she didn’t believe Alinta was disabled, she was just dying. Being with Alinta 24/7 was exhausting with her final words being “and then she died”.
Reflections of Pam’s story - Mother of Tamina

Pam’s story speaks of the possible difference of two systems of care and the confusion associated with the developmental stage of the AYA with cancer. Initially Tamina was treated in Adelaide for what was thought to be a few weeks progressing to seven months. Pam was required to move herself and her other daughter Alicia from Cairns, Queensland to Adelaide, South Australia a distance of 3,400 kms. She found the treatment in the Hospital wonderful although Tamina lost contact with her friends due to the period of time away from home. On their return home Tamina received radiation therapy in Brisbane, Queensland which was also a long distance of 1750 kms from Cairns, Queensland. Tamina was often the youngest waiting for treatment. During this time Pam was concerned that she had to leave her nine year old daughter Alicia at home on her own. Tamina continued with follow up care and regular check ups. It appears that when she was transitioning from the paediatric to the adult system this follow up care was not as assertive.

Tamina progressed into young adulthood with minimal follow up and became a mother. When Tamina had a lump on her chest and developed a cough Pam was concerned this was something sinister. The system was slow to respond and it took many months before Tamina had a chest X-ray. From Pam’s story, when the Ewing’s sarcoma re-occurred she was excluded from many of the discussions with the treating team and believed she was unable to provide the support that Tamina required at the time. Tamina died at home with Pam wishing she could have shared the experience with someone. After the final destination there did not appear to be any plan as to what to do with Tamina’s body after her death and she was transferred to the hospital via ambulance, which concerned Pam as she thought she might require an autopsy.

Reflections of Val’s Story - Mother of Anthony Charles and Susie

Anthony Charles - Adult System

Val’s account of Anthony once again reflects isolation and being misplaced in the system. Anthony was sent to his mother in Perth, (Western Australia) as his father was not coping with caring for him at his home in Geelong (Victoria); Val
had only just recently moved to Perth a distance of 4,000 kms so had no support from family and friends. Val spoke of how it was difficult for Anthony in the adult system as he was surrounded by older people, he was treated as an adult and things were explained to him in an adult way which he didn’t really understand. Some of the burden of being cared for in the adult system was alleviated with Val being able to give Anthony some of his treatment at home.

As with other stories, the side effects of treatment were difficult to witness. The social impact of being cared for in Perth was highlighted when Anthony was flown back to Geelong, as he wanted to die back home. Val, who was a single parent, could not afford to fly back and forth to Geelong and caught the train back to Geelong with her daughters. At the time she did not know where they were going to but she just wanted to be there for Anthony when he died. Val said she had little support she said “you just cope.” Like Jenny she found him dying in her arms special.

**Susie - Paediatric System**

Val and Susie were aware that she would develop leukaemia because she had Fanconi anaemia. At the time of diagnosis Susie expressed relief. Val said she felt prepared for this cancer journey as she was more aware of what chemotherapy can do to the body. Susie was treated in the Children’s Hospital and, as the other stories have said, it was difficult. Val commented on how it was hard for Susie being an adult in a kid’s world. Val stated that this time she was very much involved in Susie’s care and that the doctors consulted her with all their decisions.

The journey was also made easier with Val being able to talk openly about dying to Susie, who demonstrated how prepared she was by organising her own funeral right through to meeting the funeral director. Val commented this made it easier for her when Susie died. Apart from the isolation within the Children’s Hospital system, Susie also was isolated from other AYAs with cancer in the community. Members of the local Cancer Support Group were all over 45 and CanTeen was based in Melbourne, (Victoria) which was three and a half hours away by car. Val reflected that Susie’s journey was easier than Anthony’s and his quality of life was not as good. With Susie, because they
were prepared, she was able to enjoy her normal activities with the local GP ensuring she had blood transfusions to give her the energy to engage in these activities. Val wasn’t with Susie when she died as Val felt she needed to be home. She said Susie was in a coma and Anthony had been conscious when he died, so it was a different experience.

Reflections of Tania’s Story - Sister of Anthony and Susie

**ANTHONY CHARLES - ADULT SYSTEM**

Tania only remembers snippets of Anthony’s journey: the lumbar puncture, chemotherapy, vomiting, having to gown and glove, and him lying on the floor in pain. Although, the journey did affect her to the extent that after he died she would have nightmares.

**SUSIE - PEDIATRIC SYSTEM**

Susie’s cancer journey was more public than Anthony’s as they were aware she would develop leukaemia. Tania spoke of how she and Susie had been given the diagnosis and the consensus was – “where do we go from here?” As mentioned by Val, Susie hated being in the childrens’ system because she couldn’t engage in age appropriate behaviours or activities. Tania felt sorry for her and her isolation within the children’s system. The family assisted by always having someone with her so she could have some adult conversation.

Tania remembers a lot of things were put on the backburner as their main aim was to support Susie. Susie preferred family to provide her physical care in preference to the nurses. Once again we witness family making sacrifices in order to support the family member in a system that does not cater for the AYA’s needs. Tania spoke of how her friends in the medical field were amazed at how well Susie put up with what she was going through. As with many of the other stories Tania found it hard watching Susie hit rock bottom and being really sick with chemo. When Susie read her eulogy to Tania she found it hard as it actually made her aware of the finality of Susie’s death. Tania recalled Susie maintained her sense of humour through the journey; once again a young person seeking to maintain normality. Tania was devastated when she knew Susie was about to die; they drove down to see her and left the next day. Tania
said she would have liked to be there when Susie died; although she had spoken to her the week before on the phone, which made it easier.

**ADULT SYSTEM OF CARE**

**Fulvia’s Core Story - Mother of Jadye**

**DEPARTURE**

Jadye was a healthy, fine teenager. I remember when Jadye was in Year 10 she got tonsillitis and was really, really ill. They were too infected to take out so she was having penicillin injections overnight. When they cleared up, she had them out. There was always something wrong with Jadye’s tonsils. I used to call them big, mutant tonsils. I wanted a biopsy done on them. After Jadye’s tonsils came out, within three weeks she was saying her bum was sore. I thought it may have been a bit of pressure from lying in the hospital bed. I let it go for a few days and she kept going, ‘my bum is sore.’ I had a feel and it felt like a little sinus. We went to the GP who referred Jadye to a doctor in Wollongong. The doctor thought it was only a cyst, that we’d have a CT scan, book into hospital and they would remove the cyst. Jadye had the scan and I saw this black thing and I thought “that is no cyst”. The doctor rang my mobile and said you had better come into my office, you don’t need to book. The doctor said it was a tumour and they would have to send Jadye to Sydney to find out what it was. I recalled walking out of there in shock. My best friend said to me, “don’t fall apart, be strong”.

We went to Sydney and they did a biopsy and it was hell. The tumour was trying to come out where they did the biopsy and they made a mess of her. The tumour was bleeding everywhere and the bed reeked. They still didn’t know what it was.

**EXPLORATION**

Two weeks later they rang and said it was rhabdomyosarcoma, that they had got it early and all she would need is a little bit of chemo and she would be fine. I begged for Jadye to be admitted to the Children’s Hospital and they said no because she was 16. She was admitted to an Adult Hospital. During that two
weeks the tumour had taken over Jadye’s bowel and pelvis and she was in so much pain. I wanted time to get my head around the tumour and work out if there was any other way, but to them it was urgent that she have chemo so she had chemo straight away. According to the doctors she wasn’t going to die. They knew rhabdomyosarcoma and how to treat it, everybody got the same standard treatment.

The first time she had chemo and Jadye came home, the script was totally wrong. She was on oxycontin and instead of 10mgs every four hours they wrote 40 mgs every hour. If you didn’t know any better you would just give what the script says. The next time I came back to hospital I told the Nurse Unit Manager that I had run out of oxycontin. I told him I gave her 40mgs every hour and after three hours there were no tablets left. I then said, you’re lucky I know what I’m doing, I could have given it to her and it would have killed her.

**Anticipation**

Jadye had her full dose of chemo and the tumour went away. They said if it doesn’t come back in two years she would be fine. We had a big party. Jadye went to the oncologist saying, “look at me I’m cured.” I remember Jadye saying, “this cancer rubbish is just rubbish, bring it on.” The oncologist asked Jadye what she was going to do with herself and she said “she was going to do this and that and go to America to meet Eminem.” The Make a Wish Foundation were helping her go to America to meet Eminem. We were all excited that we were going to do something that she wanted. I did think we were really selfish taking things from the Make a Wish Foundation as they should be giving things to someone who is dying. I thought maybe we were scamming the system by taking these things.

**Exploration again**

Within six weeks the cancer was back in her spine and there was more chemo. We had been to a naturopath who had said no more chemo and we changed everything to organic and did everything we could. When the cancer came back I knew that the chemo took the pain away. When we went back to the
naturopath and explained that Jadye had gone back on chemo, the naturopath said “she must want to die if she doesn’t want to do it his way.”

I remember they made a mistake with the chemo and Jadye ended up with ulcers in her mouth and all the way down to her stomach. Her tongue was fat and outside her mouth and half of it broke off, it was outside her mouth for two weeks. Then the therapy caused problems with a nerve in the spine where the tumour was and she got foot drop and couldn’t walk. Jadye was a mess. It was torture and was probably one of the hardest times and it was their fault and it made me angry. The Professor from Sydney never rang and apologised for the mistake or anything. They were so blasé and uncaring. I remember I had wanted to speak to Jadye’s doctor and had asked the social worker to get him. The social worker came back and said the doctor had said he sees 2,000 cancer patients a year and he’s got 15 minutes for each patient and Jadye has had more than her 15 minutes. Jadye had just had enough by then. She had been through menopause and she ended up in hospital every time; neutropenic after the chemo. She would be in the hospital for days and she hated hospital.

Jadye fought it all the way. They kept giving her blood transfusions and one day Jadye said no more and the nurse ripped the cannula out of her arm and said, “go home Jadye we’re not treating you.” I don’t believe they understood teenagers. I thought “come on, she’s a teenager, she is rebelling.” I recall how many times I fought with Jadye to have her treatment, to have her blood transfusions, to do that. We didn’t need them not helping. I believe that had she been in an adolescent ward it wouldn’t have been as hard to get her there. I believe she would have had the time of her life. If the rest of them were lying there having transfusions she probably would’ve just done the same. In hospital you’re just one in a million but when it’s your child you want them to be special.

At that age it is all self-esteem and losing her hair was traumatic. We spent a lot of money on wigs and make up and those sorts of things. Jadye would get home from a week’s chemo, drop her bag, put on her wig and be out of there. I would say, “you’ve just had chemo,” and Jadye would say, “what chemo? I’m out of here.” I thought maybe Jadye was right, ignore it and it will go away.
The Cancer Council gave us a week in Cairns that was probably the best thing that ever happened to us. For some miraculous reason that week Jadye was not ill. We went to the butterfly sanctuary and Jadye just loved it, the butterflies were all over her. The butterflies wouldn’t come over me, Jadye would give them to me and they would fly off.

The first time Jadye went to the major public hospital in the city she was with three older women. One lady died in the bed next to her and the relatives chanted for 8 hours. Jadye was overwhelmed by it all. The next time she went in, they put her in with old men and it was hell. One man had prostate cancer, he was bleeding in the toilet, and Jadye was vomiting straight after him.

The whole time she was in hospital Jadye needed to be stimulated. There was nothing. We got people to massage her, we brought lots of board games, lots of entertainment, the whole family came up, she was never alone. I had to push and push to let someone stay with Jadye overnight. On the adult ward it was, “oh come on Jadye what’s wrong with you? Why does your mother have to stay here overnight?” If I couldn’t stay her boyfriend would stay and she was never left alone.

There was never anyone Jadye’s age for her to talk to. I desperately wanted her to get involved with CanTeen. Jadye didn’t understand and said, “why do I have to hang around with people who are dying? I’m not dying.” If she was on an adolescent ward she would have mixed with people from CanTeen and got an understanding. Camp Quality and CanTeen did come and try.

I wished the support from the hospitals was at their level. Jadye hated the social worker; she’d walk in and go, ‘how you are Jadye?’ I thought what’s a teenager going to do with that, especially an energetic, feisty teenager, if she didn’t like something it was out there. The social worker was not appropriate for Jadye because she didn’t know how to cater for adolescents. I was told they had an adolescence social worker. The adolescence social worker rang me once and said she would get to Jadye. We are still waiting. It wasn’t until right at the end that the social worker told them that they had an adolescent ward, which was for young people with anorexia. I believe if Jadye had hung out with people more her age it would have been more positive. The patients on the adolescent
ward were all laughing and teasing each other and being silly and that is what Jadye needed. Adolescents in a children's ward is much better because all Jadye saw was death and dying. Jadye met a lady (Jane) with breast cancer; when she asked how she was the nurse goes, ‘oh dead.’ Adolescents in an adult ward is like a death sentence, they rub it in your faces, death and dying. It's not an incentive to get better when an 80 year old in the bed next to you has prostate cancer and it is real dark and gloomy.

I thought the nursing staff were really angry and it was just a job to them. They had no compassion whatsoever. The nurses were so busy being professional and in charge that there was no one to do the hands on care. They were just too busy being experts. They don't know cancer; they know chemo, how to give it, and maybe what to do if you get sick afterwards. We did everything for Jadye, we showered her, made her bed and I wondered what happened to the rest of the people on the ward. Basically the staff was dealing with me, not Jadye. They would try and talk to Jadye with all this medical terminology and I would say, “look Jadye it's basically like this.” The staff didn’t like that. I knew Jadye, and how to speak to her, what she understood and what she didn’t.

I recall they got me aside and said no sex while she is having chemo. Every time they went near Jadye they would ask,”are you sure you’re not pregnant?” In the end Jadye said, “why are they asking me if I’m pregnant? I’m 16 years old and I’ve never had sex.” I thought it was an insult because of where the tumour was she wouldn’t be doing much anyway. I didn’t like the feeling when we walked onto the wards. I think it was because Jadye was 16 and had a boyfriend and he was Aboriginal. I wanted them not to treat Jadye as an adult but more like a child.

One time we were booked in for chemo and we were told there was no bed. It hadn’t been easy getting down there, packing your bags, getting Jadye down when she didn’t want to go, pulling over to the side of the road so she can be sick. I asked “you want me to go home and come back tomorrow.” I was basically told, “yeah.” I screamed and yelled and said she is having chemo and that’s that. This went on for hours and eventually there was a bed. It was like “I'm sorry that my daughter has got cancer, she needs chemo, and she needs it today.” It got to the point where I felt when we got to the wards it was like, “here
come Jadye and her mother.” I ended up an angry person, you’re tired and you’re frustrated and you’re fighting with them and you’re watching. The whole family suffered every time they made an error.

In the end I asked the local doctor for Jadye’s care to be transferred but he wouldn’t do it. My friend and I went to the cancer wards of all the major city hospitals and asked to speak to the head sister or the doctor. I told them my story and how I wanted a transfer and basically no one would take Jadye’s doctor’s patients. In the end I thought I don’t want to be here going to all the different hospitals I should be spending my energy on Jadye. I didn’t want to feel guilty and go I should’ve done this or done that. It was like get through this and get over this. It was like survival. It was “come on, darling let’s get rid of this cancer and put the hospital behind us.”

That’s when I went crazy trying everything. I really believed we were going to beat it and you don’t admit that you’re not. I was in fight mode; I was looking at everything, getting stuff from America. For Jadye, chemo was it, and she believed that’s because it was easy. We had 16 months of torture. We got a four week break after the first tumour and another four weeks after the bone marrow.

We could see Jadye’s body was giving up on her and she was so skinny and yet she fought it. I wished we had of talked about it (dying) but it was like admitting that she was going to go. We were all trying to be positive, it was all about healing. I found her diary after she passed and it was all about, “I cannot live in this body any longer, I don’t want to be here anymore, the pain is too much.” I did try once and asked Jadye if she wanted to talk about it and Jadye said, “talk about what?” I remember on one occasion Jadye saying if the cancer came back, she was a goner. I believe that at Jadye’s age they don’t have a proper understanding of dying. They think dying is not a permanent thing.

The second time it came back she had radiotherapy and it was fine. She then had the bone marrow transplant. It didn’t make sense to me that they took her bone marrow and gave her a bone marrow transplant. I remember everybody came and kept talking to me like I was an idiot. They said it had to stay away for six months and then stay away for a year, two years and so on. Four weeks
later it was back and it was in her bone marrow. Within a week, it was in her liver, in her lungs, in her back, in her shoulder and in her bone marrow. It is a horrible cancer, it’s cruel.

DESTINATION

They gave her radiotherapy for her liver and Jadye seemed fine. Four days after the radiotherapy I went out for dinner and when I came home Jadye was upstairs screaming and screaming. I thought it was pain from the radiotherapy to the liver and we sat on it. We rang the doctor the next day and we were prescribed morphine and more drugs for her. Within a week she started coming up with bruises. Palliative care came and I said, “we don’t need you I’ll ring you when I need you.” I stayed up with her for the next three nights and Jadye just screamed and screamed. The next morning Jadye had a black eye and bruises were coming up everywhere. I thought that is not radiotherapy pain, there is something going on. I rang the palliative care doctor who said to take her to hospital for a blood transfusion. She begged me to leave her at home and I yelled at her and made her go to the hospital and she never came home. Jade was in hospital for four or five days and she passed away which was a bit of a shock.

The first night was spent in Casualty because there were no beds. They drugged her up for pain and from then on she wasn’t herself any more. She was funny, she was hilarious. The staff at this hospital really looked after Jade and they did treat her a bit more like her age. One of the nurses brought her a teddy bear and they did special things for her. I knew Jade was dying but I didn’t understand death. She just slowly started going into a coma. She was too ill to bring home or move to palliative care. The social worker told me that Jade was not coming home. I explained to Jade that she was not coming home. Jade looked at me and said ‘is it going to hurt?’ I told her, “no, I promise it won’t hurt and I’ll be right here next to you”. Not long after that Jade lay down and was unconscious, she sort of accepted it. She had been the same for about two days when a female doctor came in and said Jade’s condition had deteriorated, she is now unconscious and she’s going to start cheyne stoking, to start breathing differently. The doctor said she didn’t want us to be distressed, it was
just the normal way of dying, there’s no pain and Jadye is not in any distress. The doctor said it could take a day or two before she passes away.

As the doctor walked out the nurses walked in and said could they change her. I had done absolutely everything for her and on that day I needed a break and I walked out of the room. The nurse came out and said they needed a hand to change the bed. The nurse picked four people, me, my dad, Jadye’s dad and Aaron (Jadye’s boyfriend). They lifted up the sheet and the nurses fixed the air mattress under her. As she was up there, she took a strange breath and as we brought her down, she was gone. We laid her on the bed and she just sat bolt upright, the first time she had moved in four days and just stared straight into my face. I knew she was gone. I feel that after the doctor left it was like Jadye said, “I’m not doing this to my family, I’m not doing another two days of this.”

I did not want her taken to the hospital morgue. The wardsman rang the funeral people and they came to the ward and took her away. It was hard leaving her body over Christmas. I felt like I was still trying to beat the cancer and Jadye was coming home. I had this urgency, like hang on, bring her back, let me have just one more go at that.

Helen and Geoff’s Core Story - Parents of Michael (Mick)

DEPARTURE

The year Mick was 20, and in his second year of his apprenticeship, he told me (Helen) he had a lump. I thought it was just a blind pimple but it was still there in four days. I suggested that if he was worried he should take himself down to the doctor.

I (Geoff) thought the system was a bit slow to react to his symptoms. There was no real urgency and they were just looking for what the symptoms might mean. They ruled out cat scratch fever and a few other viruses. They had decided to refer him to an oncologist and a surgeon so they could get the inflamed lymph node out and do a biopsy to find out what is going on. I remember being told the public system was backed up. We only had ancillary insurance so I went down to the private hospital and swiped my card and Mick was in the next day.
The surgery went well but the biopsy was inconclusive and they couldn’t recognise what it was. The doctor was not happy with the results so he referred Mick to another doctor in the public system. The pathologist told us that Mick had a precursor to acute lymphoblastic leukaemia. We (Geoff) jumped on the internet and you shit yourself when you find out what it is all about. I (Helen) remember when Mick got the initial diagnosis he just walked out and said, “let the games begin. It’s not going to stop me.”

EXPLORATION

That’s when they hit the panic button and we were given the choice of two public hospitals, one in Newcastle and one in Sydney. It was suggested that we see the specialist in Newcastle because of his success with lymphoma. I (Helen) remember going down to Newcastle for the initial interview. We had gone down the Thursday before Easter and I (Geoff) remember the specialist telling Mick he had a very serious condition and if he didn’t have treatment he would die. The specialist said unfortunately everything shuts down at Easter otherwise he would be hooking him up with some chemo today. He explained he would have four or five days of chemotherapy. I (Helen) didn’t realise that the four or five days would be spaced over a month, so when we went down to Newcastle again for the chemotherapy we had nothing with us. We were lucky to stay at the Leukaemia House. Newcastle was a good choice as we were familiar with the area and had friends down there. The police service said I (Geoff) could work down there rather than use up my leave.

Mick was doing really well with the chemo, except for the first day. He was very sick after the first lumbar puncture, with vomiting and severe headaches that lasted for days. He was in an open ward with probably four to six other people and Mick was the youngest on the ward. I (Geoff) realised that he was a young man in an old people’s ward. Half the ward was having maintenance or palliative care. I thought, saying if he didn’t have chemo he wouldn’t survive was frightening enough for Mick.

The first night he was in hospital the patient in the bed next to him had been trying to treat himself, he had bounced back into the hospital at a stage when they couldn’t help him. He was yelling at Mick, saying things like, “don’t let them
at you, don’t let them touch you with this stuff it’s going to kill you.” The next minute the patient started to have a fit and there was blood pouring out under the curtain, it was just awful. They took him away and he died a few hours later. He basically died in the bed next to Mick. This was not a good introduction to his first day in hospital. I (Geoff) think it probably scared the living shit out of Mick.

After he started treatment you could watch the chronological order of chemotherapy with his daily blood tests and whether he is getting his count back or not. He got pretty bored because there was no one he could talk to, because they were all older people. Over time some young ones did come in and he got to talk to them.

After six weeks of treatment he was neutropenic and his white cells weren’t coming up. He then started to spike a temp and he got shivers and chills and all sorts of things. They couldn’t work out what was wrong. They started hitting him with Gold Brand infection fighters, they couldn’t grow anything from the culture and nothing was working. Unbeknownst to them all, he’d picked up this fungal infection, scedosporium. Not many people live past four days with an attack of this fungus. Once they had identified the fungal infections they started him on voriconazole in IV and tablet form within 24 hours. This was a trial drug for the fungal infection. The fungal infection took over his right lung and his right eye and sent him blind.

During this time everyday someone would sit on Mick’s bed and give him some more bad news. I (Helen) remember all the different specialists who were coming in and out and Mick had nicknames for them all. The thoracic man never spoke to us; he would listen and then walk out. I had to wait for the nurses to come back in and then ask them what he had written. I (Geoff) recall that when the scedosporium had settled down they took him to surgery and basically cut him open everywhere. I (Helen) remember him getting cranky in intensive care after the surgery, because he wanted to know the time and how long he had been there. He was so determined that eventually they went and got him a clock. His hands had been taped down because they didn’t want him pulling out his drip, eventually they had to undo his hands. He was so determined.
The infectious disease guy said to him one day, “tomorrow we’re going to take out your spleen, your right lung and your eye.” I (Geoff) couldn’t imagine what that would do to a young person, particularly after already being introduced to high doses of chemotherapy. I (Helen) felt angry that they had told him they were going to take his eye out when I wasn’t there. I thought because of his age they talked to him about things when I wasn’t there. I thought I couldn’t say I wanted to be there every time they came in and said something because he was nearly 21. Although, I knew he did not have the world knowledge to ask the questions that he needed to. When I came back he said to me, “I can handle the lung, I can handle the spleen but they’re not going to take my eye.” So we called the eye specialist who said, “well Mick, I don’t really want them to take it, I think I can save it.” He told Mick his eye was stuffed but there was this new drug that he wanted to inject straight into his eye. He asked if Mick was willing to give it a go. I (Geoff) remember the eye specialist saying it had never been done in the world and was he willing to give it a try. The eye specialist deadened Mick’s eye and then I (Geoff) saw him have three injections straight into the eye. I believe Mick was happy because he was part of some ground-breaking thing and there was nothing else he was happy about. You want the guys who are on the cutting edge, because other than that no one takes a chance on you. That is how Mick lived his life, all or nothing. The eye specialist explained that if Mick did lose his eye, he would put a bit of coral in there and put a lens over it and it would move and look like his other eye.

The eye treatment became a regular thing and there was no sign of scedosporium in that eye after the eye specialist had worked on it. The treatment affected his retina so they injected his eye with gas and he had to stay on his stomach for three days and not move. The retina started to come off again so they injected the eye with oil and he had to lie on his back for three days. Then cataracts started to grow so they lasered them off. He had so many operations on his eyes. He did actually get some sight back. I (Helen) remember everyone cracking up laughing when they were in the hospital transport, and Mick yelled out, “Stop.” They screeched the brakes on and Mick said, “I can read the stop signs!” The specialist had hopes of bringing his vision up even further after the bone marrow transplant.
I (Helen) sometimes reflect on his treatment and what it did to the body, his skin, the way he did things, his mental state, his sense of taste. I think of the pain he went through, as well as the different operations and the eye thing and his very first lumbar puncture. I remember he got violently ill with his lumbar punctures, he’d be up all night vomiting and I’d be there all night. You get used to the treatments and understand them and they become less of a real shock.

We couldn’t get any physio for his feet or legs. From the side effects of the vincristine, his feet had blown up and he had no feeling. We couldn’t get physio for him because he was not elderly or incapacitated. I (Geoff) think the system is overloaded with old people but I believe young people are our future and should be at the top of the list. We did get a physio for a couple of weeks who was young and would come and sit and talk with Mick and not just do the exercises. It perked him up when he knew she was coming.

I (Helen) knew he was angry at being shut in a room when he was neutropenic. He got very angry with me at times. He wasn’t coping very well and I tried to get him some form of counselling. It was a real battle to get some mental health help. I still don’t understand it, because he was an inpatient, why couldn’t he just go downstairs to mental health and seek mental health help? A psychologist came up to see him once but she was probably sadder than he was and made him worse. When we had to return to the hospital again he got really distraught about it because he thought he was beating it and he was so low. I couldn’t get any help for him because he was an inpatient once again. I (Geoff) believed the mental anguish we went though could probably be dealt with while it was still in a minor form. For a lot of young people they give them something in a pill form. If the psychological side was managed, they’d be a lot better off in themselves and handling things better and it would help the body do its natural thing.

We (Helen & Geoff) received free counselling with the Employees Assistance Program (EAP) who said if we could get Mick to them they could help. Then the EAP suggested a young fellow in Newcastle who was happy to come to the hospital. The counsellor would come and sit for hours with Mick in his room and just talk and talk about everything Mick wanted to talk about. That made the biggest improvement in that kid that you could imagine. I (Helen) thought the
counsellor was amazing but it was outside the health system and I had to go through my work to get him. I remember saying to him, the free sessions must be over and he told me not to worry about it. He was only too happy to help this kid through. He would come anytime.

I (Helen) think it was frustration more than anger, because he was very much in control of his own life, he was working, had a car, a girlfriend, he’d been going away to surfing competitions for years with his friends. All that was taken away from him, he had just started going forward as a young adult. He couldn’t control it; he couldn’t make it go away.

He experienced a lot of isolation. It was quite a long way for other young people to come and visit him. It was hard for his friends to visit because they were at the same stage of life as him; had just got a car, and a job that didn’t earn much, and it would be hard to come down for the weekend and find a place to stay. I (Helen) think if he had been at home people would have popped in after work and kept him in the loop. He would sometimes ring his friends at night time and they would be going out somewhere and he thought they didn’t think about him. I explained to him that he couldn’t expect them to stop doing what they were doing and when he was back home he could start doing things with them again.

If there were other young people in the hospital they were drawn to each other, they were in and out of each other’s rooms. If there were no other young people in the hospital when they walked in they just didn’t want to be there. I (Helen) remember the relationship Mick developed with two other young fellows. When they couldn’t be in the same room because they were neutropenic, they would ring each other through the wall. They became quite close.

There is no alternative because if you want the best treatment that’s where the specialist and the high volume is. I (Geoff) believe you need to hook up with the university-backed hospitals because that is where you get the guys who are cutting edge, they’re on top of everything and they think of everything.

I (Geoff) remember Mick getting to the front door of the hospital and patients and staff were out there smoking, there were thousands of cigarette butts on the ground. Mick used to say, I’m over this and he’d say I’m not going. I (Helen)
recall that some of the wards we had to walk through at night to get to Leukaemia House were scary. The security guards used to walk me back at night. There were a lot of dodgy people around there, they used to have a lot of robberies and assaults, with young people going through the hospital stealing stuff out of people’s rooms. When I got back at night I had to text Mick to let him know I was safe before he could go to sleep. I (Geoff) think it is hard that young people with a terminal illness get shipped to a hospital that was built in the 1900s or whatever and that the people supporting these young people are in patchy accommodation which is basically a gift from someone else.

I (Geoff) worried about the way death was managed. The young guys knew that the trolley was going to the morgue and distressed families would be coming in and I worried about how that would affect Mick.

The best thing we ever did was to get him a laptop. He somehow managed to connect himself to our internet service from the hospital. He could get online and chat to his friends. He also broadened his friends that way. Most nights he just wanted to get on the internet and talk to his friends.

We (Geoff and Helen) made extra signs to protect him, we’d ask people if they had a cold and if they’d washed their hands. The bottom line was, if you’re crook, don’t turn up, you can talk to him on the phone or computer. That type of memory would never go away, you’ve got to protect your own. A few times Mick wanted a hug or a kiss and I (Geoff) would be thinking in the back of my mind, am I coming down with a cold or something? If we were going to get sick that would be the time because we were under so much stress.

Mick hated hospital food so we would buy him organic food. We had been told by nutritionists he shouldn’t have dairy products or sugar, with lymphoma. The hospital diet was based on the stuff that the nutritionists said don’t touch. We bought organic fruit and vegetables and organic juices. He ate almond after almond and organic cherries, he had a permanent red mouth because he ate so many cherries. I (Geoff) would cook up organic beef and chicken stir frys with vegetables and smuggle them in while it was still hot. I was bringing the food in against the advice of the Hospital and there were signs everywhere. The hospital gave up with us because they knew we only had to get it across the
road and we were taking every precaution. The specialist told me that Mick had not wasted away like the other patients. I believe if you are relying on hospital food you are not going to get any nutrition.

I (Geoff) believe that sometimes you have to take things into your own hands. Everything we tried to do gave him every possible chance. We just didn’t know this stuff and you need to talk to people who knew this stuff because it is a minefield. Mick took paw paw leaf extract that we ordered over the net. A young guy had told Mick how the Aboriginals used it to fight cancer and his mother who had cancer had lived on it. I (Helen) believe the paw paw extract probably kept him healthier than if he hadn’t have had it.

We worked it out between us so we could always have someone with him. I (Geoff) believe we’d have been no good to him unless we were on top of it. Geoff went down the second time because I (Helen) believed I may have smothered him a little bit the first time, I was with him all the time. I do recall sitting with him one day when he was sleeping and looking at him and thinking why, just over and over again. He woke up and I said, “sorry Mick I didn’t mean to wake you.” He said, “that’s all right I feel safer when you sit next to me.”

I knew he could tell that Geoff and I were stressed not being together. He told me that when this was all over he was going to buy us a big four wheel drive. He just wanted to make up for all he was putting us through and was concerned about the effect he was having on us. When he started receiving Sickness Benefits he used to say to me, you can take money out of my account, that it was mine.

His girlfriend couldn’t handle it and didn’t see it as very serious. I (Helen) recall the first week he went back in after remission she left him. I think she thought, you don’t look the same anymore, you don’t seem the same anymore, you haven’t got a job. But he had a wide range of friends, girls and boys. One ex-girlfriend would ring and email and stay in touch. There was a beautiful girl he had gone to school with who was living in Newcastle who was there nearly every day and she gave him a real boost. She was a real friend and really kept him going.
Because he was in hospital so often the nursing staff built up a real relationship with him. Anything he wanted the nurses would get for him, he was a bit cheeky like that. One time, when he was angry with me, after I had left the nurse told him he shouldn’t talk to his mother like that. The nurse then told me he came up to the desk and said, “I’m sorry about talking to Mum like that, do you still love me?” The nurse said what else could she say and he sat there with her for about an hour at the front desk. I have been told the nurses got hit pretty hard when he died.

I (Helen) sometimes felt bombarded by information and believed there are questions I should have asked but I didn’t think of them. I believe Mick wasn’t capable of making all the decisions and needed guidance and help through talking to someone. He didn’t really understand because we didn’t completely understand either.

I (Helen) remember the family meeting after his surgery for the fungal infection where we were given three choices, “you can go home and not do anything and take pot luck, you can stay here and have intensive chemo and take the risk of the fungal spores coming back, or you can go home, recuperate, and we’ll put you on a series of tablet chemo which won’t make you neutropenic.” He chose the tablets. I sometimes wonder if he made the right choice. Maybe taking the tablet or injection of the antifungal medication could have suppressed the fungus and having full chemo might have kept the leukaemia at bay. I think there is not enough known about the fungus. He was an exception because no one had lived with it past three days, let alone had three doctors cutting things out and still coming out of it. I (Geoff) remember that the oral chemotherapy was to keep everything at bay so that when he had the next heavy lot of treatment the scedosporium wouldn’t come back. You could tell when the blood drained out of medical people’s face that they knew he wouldn’t make it with the intensive chemo.

I (Helen) remember when he came home he wanted things as normal as possible. He wanted to get back to work. I think he wanted to feel like he was still in charge of his life. Mick knew he would never be able to function like he did before. I (Helen) tried not to be too over-protective. He didn’t go out much, maybe the occasional barbeque. He couldn’t surf anymore, because he had lost
all the sensation in his feet and he couldn’t stand up properly. The main thing was his hands and his feet, he was forgetting to wear shoes and if he cut his feet he wouldn’t know. His levels were low and he could get an infection easily. His skin was so thin and we had to get special stuff for him to wear because just walking around he would get sunburnt. He was on prednisone every second week and you knew which week he was on because on it he was a completely different person, he would get so angry and demanding. It really played havoc on his mind set, there are a couple of holes in the wall from times he got so angry.

We got him back clear again and we went to see a specialist who I (Helen) thought didn’t know how to smile, it is nice to have a friendly face. The doctor told us they had found a bone donor for him in Spain and were ready to go. The specialist said that Mick had scared the living shit out of him and said he had lost a whole ward to that fungus last year. The specialist said he had never seen anyone with resilience like Mick’s (Geoff). I (Helen) thought he’d done so much and come through so many things that he couldn’t not come through. I (Geoff) remember that Mick always thought he was going to come out of it and he kept telling people he was not ready to die yet.

The week before the transplant we camped overnight. Mick put on a wetsuit and went out and surfed. He told us he couldn’t feel it but he knew what to do by instinct. Mick told me (Geoff) the next day that he had a bit of a lump coming up again in his neck. So, he had a biopsy done at Port Hospital. The pathologist who did the needle biopsy said there was evidence of blast cells. The pathologist said to pick them up in such a small biopsy he would be making his way back down to see the specialist in Newcastle. His blast cells came back at a million miles an hour. So we made our way back down to see the specialist. Mick started getting headaches and when we got to Newcastle they said they didn’t have a bed. We wheeled him into A&E and they found him a bed. The oncology beds are choc-a-bloc all the time but if you go in through A & E with something acute then they have to find you a bed (Geoff).

They hit him with a dose of chemo, but during that time his lymphoblasts had got really high and his potassium levels built up so high he had an arrest type thing. It was touch and go for quite a few hours. The doctors had told me
(Geoff) during that night that it would only be a couple of hours. Geoff had taken
him down for the chemo and I (Helen) couldn’t make it in a couple of hours. I
got there as soon as I could.

When I got there the next morning I couldn’t believe it, he had blown up like you
wouldn’t believe with all the fluids. He just grew and grew, he went from a 65kg
athlete when he started treatment up to 120kg, he doubled his body weight. His
skin was so tight when you touched it I (Helen) was frightened it was going to
break. The staff told me they had never seen a heartbeat do what his did during
the night. They even had the piece of paper strapped to the wall of intensive
care because they had never seen anything like it. Once he had the attack with
the potassium levels nothing seemed to work.

I remember he had two or three bad nights with like epileptic seizures that broke
a couple of vertebrae in his back. They thought it had gone to his brain. When
he had one of his seizures, when he came out of it, the doctors said he looked
at one of the doctors with his one eye, pointed and said, “you’re the only one
that did anything good, you can have a gold star.” He had a strange sense of
humour like that. I (Helen) remember they tried a few other things but his white
cells just kept coming back.

DESTINATION

I (Helen) recall the doctors coming in and saying there was nothing more they
could do. Mick just looked at us and said he was not going to die. “I don’t feel
like I am dying.” He was playing Chinese checkers with me at the time.

The local specialist told me that once his white cells were over 200 he’d be
gone. They got to nearly 700 before he died. I believe he just didn’t want to give
up and he just kept fighting it and fighting it.

Even though he didn’t admit he was dying he would say odd things now and
then about if he did die. Things like, “I don’t want a cheap casket, I want timber,
who’s going to look after my stuff if I go and don’t let Ange (his sister) drive my
car.” In the last two months he started reading the bible, his boss had been
reading the bible to him over the phone and that gave him a lot of strength.
Every night he’d say the Lord’s Prayer with me (Helen).
We took him home to the Base Hospital so the rest of the family could be with him. They had him on high levels of morphine and we used to have amusing conversations, things like “Mum, why am I cooking all the food for the hospital?” And, “is it alright if I go on Wheel of Fortune?” He racked up a $1,000 phone bill in the two weeks before he died. I don’t know who or where he was trying to ring. He wouldn’t have known, he had that much morphine in him (Helen).

People would come and see him at the Base Hospital. His ex-girlfriend walked in and he said, “you’ve dyed your hair.” I (Helen) couldn’t help it and just laughed, no hello or anything. I remember he was lucid and would slip in and out of different worlds. He would say something that had meaning to some people and then he’d go off for a couple of hours (Helen and Geoff).

We spent the last few nights in hospital with him. I (Helen) remember on the Sunday morning before he died he wasn’t very lucid and was not actually talking but making a lot of sounds. That night he had been in quite a bit of pain and they had upped his dose. The next morning he kept wanting ice to suck. He’d lay there, crunch his ice, smile at you and then go back off again.

A friend of ours from Newcastle, who was actually the Head Nurse down on his ward and who had known Mick before he got sick, was up for the weekend and back to work on the Monday. At this time his breathing was very laboured. The friend was just about to leave and she went up to him, gave him a kiss and said, “don’t make it too long now Mick, it’s too hard for you.” Before she walked out of the room he was gone. I (Helen) believe it was like she had given him permission.

**Reflections of Core Stories in the Adult System of Care**

Fulvia, and Helen and Geoff’s core stories are exemplars of the experience family members when the AYA is cared for in the adult system. This study provided two exemplars for the adult system as the majority of the stories are of this experience. As with the other core stories (Appendix J), summaries which are reflections of the themes and issues of the core stories follow.
Reflections of Denise’s Story - Mother of Brenton James

As with many of the other stories Brenton James was required to have his operation, for the removal of his eye, in a metropolitan area away from home. There was a huge sense of relief when the operation was over and the family resumed their normal life. The family was told the operation was a success and Brenton James had as much chance of getting cancer as the normal population. Denise was shocked when it was diagnosed in the liver. As with others, watching Brenton James have his treatment was hard. He had the look of someone who did not have long to live.

Communication was also an issue for Denise as she became frustrated with the way it was communicated to her that Brenton James was going to die. Unlike others, Denise found the social workers always kept her in the loop and her employer paid her the whole time she was off work. She like others found the dislocation hard with not having close family and friends to support her. Brenton James, similar to all the AYAs in this study, sought to be normal and to protect family and friends from his suffering. Denise spoke of how sad and emotional this was to watch at times. In contrast to Deborah and Irene, Brenton James and herself wanted to go back to Peter MacCallum Hospital Melbourne for the end as Brenton James felt safe there. As with Jenny, Denise and Brenton James developed a deep connection with each other that enabled them to talk about everything. AYA issues were evident in their communication and, in particular, Brenton James not wanting to die a virgin. Given the choice like Val and Deborah, Denise chose not to prolong his suffering. It was important for her to be there when he died but she missed the moment. She had never expected he would go without her being there. She was grateful that they were allowed to stay with the body for as long as possible after he died, and she appreciated how the specialist spoke to Brenton James as though he were still alive. She mentioned that it was difficult for her to leave the body in the hospital morgue when they went home.
Reflections of Heather and Cathie’s Story - Mother and Sister of Paul Vincent

For Heather being told that Paul Vincent had leukaemia was the worst thing. She like others talked about watching the side effects of treatment and referred to it as the horror part of the cancer journey. Cathie spoke about how cruel the experimental treatment they gave Paul Vincent was. His eyes were burning and he couldn’t see. He looked terrible. Heather said “you let him suffer because you wanted a cure”. The doctors had always told them there was hope.

The adult experience was not positive for Heather with her saying how awful it was for Paul Vincent to be cared for in a six bed ward with older men. She said the staff worked hard to make his stay comfortable. Cathie believed this was because of his age and that she worked in the hospital. Heather was grateful he could have some of his treatment at home. Cathie was pretty much involved with Paul Vincent’s care, she found it exhausting. Her extra roles of caring for Paul Vincent as well as her role as a breast feeding mother, a wife a daughter-in-law and a nurse resulted in her feeling she wasn’t coping and she got down to six and a half stone.

The thread of the AYA seeking to be as normal as possible and protect others from his suffering, is evident in Heather and Cathie’s story. Paul Vincent sought to stay in contact with his friends and, where possible, engage in physical activities. The cancer journey had an effect on the family dynamics with Cathie speaking of the wedge that developed between herself and her father. Cathie believed her father was not realistic about Paul Vincent dying. Cathie and Heather speak of his death as being possibly the worst memory. Unlike Val, Deborah, and Denise who decided that they did not want any life saving measures for their loved one, Paul Vincent was resuscitated after a cerebral haemorrhage and he lived for another six hours. Heather just wanted his suffering to be over.
Reflections of Heather and Trish’s Story - Mother and Sister of Paul Vincent

Trish and Heather expand on Cathie and Heather’s story with mainly Trish speaking of what the experience was like for her. Unlike Cathie, who because of her role as a nurse, being very much involved in his care and having a greater understanding of what was going on, Trish provided a support role and gave testament to the journey that Paul Vincent travelled. Initially she did not associate the word leukaemia with cancer and believed he would be OK. It was not until she witnessed the side effect of treatment that she knew this was more serious. She said she always lived in hope and did not know how to approach the issue of dying with Paul Vincent. She recalls when he was first admitted it was sad and hard seeing him with decaying and stinky old men. Paul Vincent’s attempt to protect others is retold by Trish who spoke of how brave he was. He never let on how sick he was even when he was the sickest of the sick, and he never complained about the treatments. She remembers that because of this he matured during his cancer journey. He was just a young kid when he was diagnosed and he died a man, both physically and in attitude. She spoke of how witnessing the treatment and its side effects was pretty full on physically and emotionally. Like others in this study, Trish was relieved when he drew his last breath.

Reflections of Alan, Marilyn and Rebekah’s Story - Father, Mother and Sister of Naomi

Alan, Marilyn and Rebekah provide another distressing account of their cancer journey, when they told their story about Naomi. This family’s initiation into the cancer journey was a medical emergency. Within 24 hours of Naomi developing breathing problems and palpitations, she was in ICU and having chemo. Naomi was transferred to the haematology unit which for her was not a healing space; the hospital ward was drab, one woman was vomiting, another was unable to control her bowels and another was emaciated and being tube fed. Like the previous stories in this chapter, this was not a place for an AYA recently diagnosed with cancer and this experience was described by Rebekah as
horrible. Added to this were the horrible side effects of treatment and the pain that Naomi endured.

Rebekah also described Naomi’s experience of going for three days without food, as her colonoscopy kept being delayed, as torture. Other experiences which they found frustrating, while Naomi was in hospital, included waiting for procedures, the hospital food, the cost of hiring a TV and no activities. Alan commented that he knew the Children’s Hospital had recreational equipment that was not available in the adult system.

As with the other family members in this study, wherever possible the family sought to stay with their loved one as much as possible. This was difficult and required sacrifices. Marilyn often had to sleep in the armchair by Naomi’s bed in order to be with her. The intensity of being with Naomi meant at times they did not have the time to have an adequate diet, living on take-aways.

Once again we witness the AYA protecting the family from their suffering, as with Naomi not letting on how much pain she was in even though the family knew she was suffering. Communication difficulties with health care professionals was evident once again, with Rebekah speaking of the doctors not listening to, or spending enough time with the patients.

As mentioned in most of the stories, seeking normality was prominent for Naomi with her celebrating an early 21st birthday, going on holidays with the family and enjoying cuddling a joey (a baby kangaroo) which had been smuggled into the hospital. Alan’s story at one stage speaks of the difficulties of dying in a curative system when a doctor, who knew Naomi’s situation, was required to advocate for the emergency doctors not to do any invasive procedures as Naomi was terminal. This is also evident with a resident doctor who, the day before Naomi died, stated he could not give an order for Naomi to be catheterised as the policy required that an antibiotic bag be initiated.

Sadly, we are told by Rebekah of the lack of compassion and care of one nurse who helped Naomi back into bed, the day before she died, and treated her so roughly that Naomi was in distress and pain. The thread of wanting to be present at the death was also there in this story, with Naomi’s sister Sarah being concerned that she missed the moment. For Alan it was a shock when
she died as, even though he knew she was terminal, he believed that she would live. Care of the body after the death was also a part of this story with Marilyn and her sister wishing to bathe the body after death, and Alan not being able to do this as he wanted her to maintain her dignity in death as she did in life.

**Reflections of Arlene’s Story - Mother of Mathew James**

Arlene’s story emphasises the difficulties of a mother trying to determine the age appropriate boundaries as she cares for Mathew James. Her comment was that, because of the cancer, the apron strings were never really cut. This resulted in conflict as Arlene weighs up what she wants do as a mother of a young man with cancer, with what she knows Mathew James wants from her, and what she perceives are the expectations of the hospital staff with regard to a mother providing care to a young man. She stated that the medical staff couldn’t understand her level of involvement in Mathew James’ care. This involvement and conflict was highlighted when Mathew James had his stem cell transplant. She said she felt judged and didn’t do the things she wanted to do because she felt the staff would believe that an 18 year old boy should not have his mum fussing. She had wanted to stay overnight with him, like some of the partners and children of older patients, but thought he wanted his independence and that is what the staff wanted as well. She did not find out until near the end of the transplant that he wanted her to stay.

Once again the apprehension of being surrounded by old people is evident. Arlene described how Mathew James hated waiting for radiation therapy with old men with fungating wounds. The recurrent thread of courage and seeking to protect others from their suffering, is also evident in Arlene’s story. Mathew James maintained control to the end, making the decision to take the tube out of his lungs, so his lungs would fill up with fluid and he would die. He insisted on a private room he didn’t want to be surrounded by old people.

Despite his courage and independence his connection and bond with his mother was still strong. He requested that his mother explain to his friends and girlfriend what would happen. He didn’t want his girlfriend to see him after the tube was out, as he wanted her last memory to be positive. Arlene was the one to stay. As with most of the stories, the desire to be present when Mathew
James died was important. Towards the end Arlene found it difficult to sleep because she was concerned he might die when she was asleep. She retells the last moments of him struggling for breath and wanting him to go. She believes it was only when she gave him to God that he took his last breath. She describes, her final memory of Mathew James, the picture of the “Scream”. Because of this she decided to see him at the funeral parlour so she could see him at peace. She managed to stroke and talk to him and say her goodbyes.

Reflections of Sue’s Story - Mother of Ben

Sue’s story like others is painful to listen to as she tells a story of sacrifice and courage as she seeks to stay connected to Ben with his unpredictable cancer journey. At the same time Sue had to assimilate other family crises. Sue talks about how she feels guilty that she didn’t get Ben to the doctor early, but because of Ben’s busy life he was difficult to pin down. Once he was diagnosed Ben wanted to engage in his normal activities so Sue scheduled his specialist appointments around these. She recalls every time they went to the specialist he would suggest another procedure. Sue recalls how it was difficult to accept that Ben was going to die as he was just becoming a man.

Once again, communication with health care professionals appears to be an issue. Sue spoke of how the topic of death and dying was not clearly articulated by the medical staff and she feels angry about this. At one point, when Ben was going into a coma and they were in the Emergency Department, she heard one doctor say it’s terminal which she found hard to deal with.

Ben, as with the other AYAs, did everything he possibly could despite the cancer. He organised with the specialist to delay one operation so he could attend a Venturer camp in the mountains. Sue remembers some of the things he did were amazing. He dealt with his changed body image by telling people that his scars were a result of a shark attack and making light of his bald head. Added to this was like others Ben protected her, he never complained no matter how much he suffered. Sue believes this is what helped her get through it.

Unlike others who were dislocated from their home, Ben did not experience the isolation from his friends as he was cared for in facilities close to home. Sue commented on how amazing his friends were in that they stayed with him to the
end. This is similar to Thomas who died at home and his friends lifted his body onto the undertaker’s trolley.

As with other stories, the horror of the treatment is in the forefront of Sue’s story. This was compounded by unexpected medical crises that occurred during treatment, for example when his drain started leaking and they had to go to the Emergency Department. Ben had to be admitted into the Paediatric ward, under another doctor who stopped the leak but couldn’t remove the drain as Ben was not his patient. Sue’s story furthermore speaks of waiting: waiting for the doctor to come and fix the drain, waiting in the emergency department to be admitted to hospital when the tumour had metastasised to his spine, waiting for a CT scan to be performed only to be told that they couldn’t do it that night. As with Brenton Duncan, Ben’s care did not appear to be coordinated and there was no plan as to what Sue should do when confronted with the crises that occurred during Ben’s cancer journey. Added to this were the other crises that were happening in her family - her daughter falling from a balcony in Brazil resulting in brain damage, and her husband George becoming profoundly depressed and requiring hospitalisation. This resulted in her sitting on her back steps screaming, because she didn’t know what to do although she knew she needed to be with Ben.

Similar to Naomi, when Ben was admitted to the oncology ward Sue found the décor horrendous. She said the paint was peeling off the walls and the colour made you sick. She said Ben hated being in hospital and wanted to be home. Sue took him home, however she found him too difficult to manage after he had a fall and an epileptic seizure. He was admitted to a Hospice where the staff were caring and his private room bright. He was able to make the room his own. Interestingly, Ben was the only young person who died in a Hospice. The staff commented that he was the youngest person they had cared for and they appreciated the laughter that his friends brought to the place.

Sue mentioned that the topic of dying never came up and she hopes he knows she was always there for him. She regrets missing the moment of death and says she can’t forgive herself as she wanted to be there. When Ben did die she was in shock and was dependent on the staff to tell her what to do. She speaks of feeling unsupported throughout the journey. Of particular concern was that
her husband, because of his depression, was not there for her and she needed him. Viewing the body after Ben died was also important for her. Sue said he looked so calm and peaceful and it was very hard, she just wanted to pick him up.

**Reflections of Lauren’s Story - Sister of Grant**

Lauren’s initial reaction to Grant’s diagnosis was disbelief. Once again the horror of medical procedures rears its head with Lauren being distressed at seeing Grant after his nose biopsy. This initiation into the cancer journey was difficult for Lauren and was made more difficult by a nurse telling her not to cry. Lauren said this was the only negative experience she had with health care professionals during the journey. We are reintroduced to how health care professionals’ communicate information, with Lauren and her father and stepmother being told the real story and not Grant and her mother, which resulted in Lauren feeling burdened with responsibility.

As with Naomi and Ben, the environment in which Grant was treated was not conducive to healing - being cared for in what Lauren describes as dark and dingy wards. Despite the environment and unlike others stories, Lauren said Grant’s care was holistic and the family was considered as well as was Grant. This suggested a coordinated plan of care.

The continuing thread from these stories of being in a room full of ‘oldies,’ is also evident in Lauren’s story. She believes Grant was lonely and she said he was always treated as an adult in the adult system. Due to the loneliness and isolation Lauren researched support groups for young people with cancer and discovered CanTeen. It is interesting that Lauren was required to do her own research and that the hospital at the time did not provide this information.

Lauren remembers the week they were told Grant was in remission was an exciting time. They decided to get a tattoo together as a reminder of what he had been through and survived. When they found tumours in Grant’s lungs five months later, it sunk in that he was going to die. She recalls the treatment was different this time and it was as though the medical profession had given up on Grant. Lauren thought though that there was nothing more they could do and she felt horrible. Although Grant and the family were aware he was going to die
they never gave up hope, as has been seen in other stories and in particular Fulvia, Sue and Cheryl.

As described in other stories, family roles changed during the cancer journey. Lauren saw herself as being an advocate for Grant’s care. She explained it had always been that way in that he was her little brother and she had looked after him all her life. Her expanded role involved supporting her mum so she could be with Grant. She was also required to tell her mother the truth of the situation and this was horrible as she felt like she was breaking her mother’s heart. These expanded roles were in addition to trying maintain her life as a young adult with the relevant commitments. The journey took its toll when, a few days before Grant died, she had a panic attack. She believed it was because there was no way to relieve the stress.

The constant thread of the young person protecting the family is also seen in Lauren’s story, with Lauren saying Grant supported her even though he was dying. On the day he died he said to the nurse he didn’t want his family to worry. The recurrent thread of wanting to see the suffering end is told in Lauren’s story as she comments that he would be better off dead as he wasn’t living, he was existing and suffering. The waiting for the last breath is also told by Lauren, and she saw this as a bit morbid.

Lauren speaks of the compassion of the nurses who hugged them when Grant died and allowed them to spend as much time as possible with the body. Lauren remembers staying with the body until it no longer looked like Grant. Lauren felt connected in a spiritual sense after his death when she dreamt that Grant walked out of his hospital room into a bright light and he looked back and gave her a cheesy grin. She believes it was Grant saying he was OK.

Reflections of Shane and Andrea’s Story - Father and Stepmother of Grant

Shane and Andrea’s story follows a similar progression to Lauren as they give meaning to Grant’s cancer journey. As with Kristie and Ben there was an initial delay in the diagnosis and, like so many other stories dealing with the effects of treatment, it was difficult. Shane described how Grant’s initial chemo almost
killed Grant and because of this Shane was a mess. Shane’s description of chemo was of a roller coaster ride, you would think everything would be going well and then he would be back in hospital. Andrea commented that going through these ups and downs was terrible. Like Lauren, Shane and Andrea mentioned how caring the treating team members were.

The recurring thread of isolation was mentioned both for Grant and for them as a family. Shane mentioned that Grant’s friends dropped him straight away when he was diagnosed with cancer, believing they were too young to understand the cancer. This is in contrast to Ben and Thomas whose friends remained loyal and supportive. Grant was also isolated from other young people with cancer. Shane mentioned that there were four other young people being treated for rhabdomyosarcoma, all in different places. Grant was hoping to meet up with one man, but because of treatments and the side effects their schedules never seemed to fit. Shane said Grant had no one to talk to but Shane and Andrea described CanTeen as a great help, saying there appeared to be no other services for young people with cancer.

The aesthetics of the hospital environment once again appears in Shane and Andrea’s story with Shane describing one ward as being death and destruction. Like Alan, they mentioned there was nothing to do to the extent that they donated a TV and DVD player that stayed in Grant’s room.

When the family were given hope and told that Grant was probably in remission, Shane was confused as to why Grant wasn’t getting any better and was concerned because of his lack of energy that he was depressed. When he developed a cough and they were told the cancer had disseminated into his lungs, they knew that he would not survive. Grant found the word ‘terminal’ difficult to deal with but didn’t mind ‘incurable’ thus emphasising the importance of language when giving bad news.

Once again Shane and Andrea’s story speaks of the courage of the young person as Grant planned his own funeral and where he wanted his ashes spread. His motivation to care for and protect others was also evident in Shane and Andrea’s story, as Shane speaks of how Grant was concerned for his mum.
This story also speaks of the sacrifice that family members made in order to care for the young person. Grant’s Mother was with Grant 24/7 sleeping in a recliner by the bed, whilst, Lauren gave up blocks of her university studies. As with other stories the cancer provided the opportunity for bonds to be strengthened within the family, Shane stating that Grant was a bridge builder.

Shane, described how he, Lauren and Grant’s Mother were there at the end. Andrea like Irene, Deborah and Sue felt cheated that she was not there when Grant died. Shane found the dying hard to watch, saying it was killing him to the extent that he begged the doctor to given Grant more medication to end the suffering. Shane does not describe the moment of death and highlights how Grant said goodbye and apologised to the nurses, emphasising Grant’s generosity till the end.

Reflections of Cheryl’s Story - Mother of Paul Malcolm

Cheryl’s journey was different to the others as it was a public journey with lots of community support. She thinks this may have mitigated things that may have been happening in the hospital. She said when Paul Malcolm was in hospital there was someone with him all the time. This was both good and bad as Cheryl feels she didn’t get any private time with Paul Malcolm. When Cheryl heard that Paul Malcolm was going to die she thought this was unrealistic, as she believed he was a mighty man of God.

As with the others, during treatment and wherever possible Paul Malcolm engaged in normal behaviour. The day after he had been discharged from surgery he was on a leadership camp. He also attempted to normalise the scars associated with his brain surgery. Cheryl understood they were trying to live life and think about the future. She felt conflicted during the cancer journey with her belief in what God could do and the reality of the diagnosis.

Cheryl recalls Paul Malcolm went downhill very quickly and she didn’t have time to plan, as it was difficult to take the medical information on board. He became deaf, blind and very frail and they had to shout to communicate with him and this was difficult for others on the ward. Issues of communication were also evident in Cheryl’s story as she spoke of how the nurses would talk over Paul
Malcolm and say things that never would have been said if he was seeing and hearing.

The extra burden of being a single mother was also evident in Cheryl’s story. The expense of having someone in hospital was offset by the generosity of her extended Christian community. Although she did speak of not being aware of the extent of things that were happening with her other two children, until after Paul Malcolm died.

Throughout the journey Cheryl was conflicted with the visions God was giving her that were different to what was actually happening. The night Paul Malcolm died she said he was so sick that either way would be a relief.

The moment of death was also important for Cheryl as she believed Paul Malcolm was prepared and secure in where he was going. She had prayed for angels in the corner of the room and she believes Paul Malcolm was looking over her shoulder at the angels in the room. She noticed his spirit left his body ten minutes before he died and she knew then that the person in the bed was no longer Paul Malcolm.

CONCLUSION

Paediatric and Transition from Paediatric to Adult System of Care

The core stories and reflections of the core stories of the family members whose AYAs were cared for in the paediatric, or in both the paediatric and adult system, all speak of feeling out of place in the hospital system. Within the paediatric system, family members spoke of the loneliness and isolation and being surrounded by babies and younger children when the AYAs were betwixt and between adulthood and childhood. Although, the majority of the family members knew the AYA was getting the best care and there were no other choices.

In some cases the paediatric system acknowledged this displacement for the AYA, as seen in Jenny’s story in which allowances were made for Brenton Duncan’s age by allowing his girlfriend to stay over. For Kerry she was overwhelmed by the paediatric hospital environment and had difficulty negotiating the system. Brenton Duncan was required to make the transition from the paediatric to the adult system, which Jenny and Brenton Duncan found difficult being surrounded by old men. Jenny described the
experience as very, very sad and hard. The transition was so difficult that Jenny believed there was no choice but to care for Brenton Duncan at home when he was dying. This care at home Jenny found hard and difficult. Jenny said there was no coordinated care and at times she felt overwhelmed with the responsibility. This difficulty with transition was also true for Tamina when there was a delay in diagnosis when her Ewing’s sarcoma reoccurred. Pam found this transition difficult as she was excluded in a lot of the decision making once Tamina made the transition into the adult system.

For all the family members, watching the side effects of treatment and the aftermath of operations was difficult. Kerry described the experience as horrendous and like a horror movie. Many felt unprepared as to what to do, resulting in feelings of hopelessness and helplessness. This was evident in both Josephine and Kerry’s stories.

The family members all made sacrifices in order to care for the AYA, both financially and physically, which many described as hard. This was particularly evident for single parent families, where there were issues of who would care for other members of the family and feeling guilty that the AYAs’ needs took precedence over other children in the family as described by Deborah. Added to this is the financial burden that many families experienced. In Cameron’s story his mother gave up working to make it possible to care for Kristie. This was also an additional burden for single parent families, with Kerry describing how difficult the experience was of trying to provide for her family when she gave up work (as a teacher) and was required to budget on a Carer’s pension. Added to this was the stigma of not being able to provide for the family as she was a single parent. Deborah also commented on the financial problems.

These financial difficulties and difficulties of caring for other family members were compounded if the AYA was required to seek treatment away from home, with the resultant dislocation. This dislocation could occur within the family member’s own state whilst others were required to be cared for in other states, depending on the circumstances and distance. This was seen with Pam where Tamina’s initial treatment occurred in Adelaide, South Australia, which resulted in Tamina losing contact with most of her friends in Cairns. She also had to travel the long distance to Brisbane, Queensland for treatment on her return, which Pam found difficult. As a result of having to travel to Brisbane, Queensland Pam was required to leave her nine year old daughter, Alicia, at home. This further compounded the sense of isolation, as there was
no family or friends to support the AYA and the family members on this journey. Some family members spent months away from home whilst the AYA was given treatment. Val felt particularly dislocated in Perth Western Australia with no friends or family. Further to this some family members were required to travel long distances for day treatment. Kerry found it particularly difficult having to travel the 200kms to Brisbane, Queensland for radiation treatment and not be provided with accommodation as Alinta was seen as an outpatient. This is further demonstrated with Cameron’s story where Kristie received her chemo in Brisbane, Queensland. This dislocation resulted in further sacrifice and more financial hardship.

Overlaying this was, at times, difficulties with communication and a lack of understanding of life stage issues for the AYA. In some situations the family members were required to advocate for the AYA in order to have their needs met, as was seen with Deborah insisting that Matthew Anthony be allowed to die at home and Josephine insisting Christopher be given more morphine. Also, there were problems with the way the information was told to the family members with many believing the way the information was told was confusing or lacked empathy. For some of the family members in this study where the AYAs were cared for in the paediatric system, there appeared to be a sense of co-coordinated care with parents being involved in the decision making and being provided with information. Although, both Jenny and Kerry believed that the care was uncoordinated and there was a sense of no choice as to where the care was provided. This lack of co-ordinated care was more noticeable for Jenny and Kerry when Brenton Duncan and Alinta were dying at home, which they both found exhausting and hard.

The dying was hard for all the family members although many found comfort in the way the AYA died, which was more evident for those whose AYA died at home. Finally, throughout the whole journey the family members were amazed by the AYAs resilience and strength of character in the way they confronted the cancer journey. Irene commented on how well Thomas handled his amputation and Jenny saying that Brenton Duncan made the dying easy for her. Added to this was the disruption in normal developmental stages, with Cameron noting that Kristie missed out on what a normal teenager would do. Nevertheless the AYA attempted to engage in normal behaviour whenever it was possible, such as Kristie going to school and schoolies and Thomas having his friends visit regularly.
Adult System of Care

The core stories and reflections on the core stories of family members whose AYAs were cared for in the adult system, demonstrated similar accounts as to those who were cared for in the paediatric system in that the family members and the AYA found it lonely and isolating. Although in these stories there was more of an emphasis on the aesthetics of the adult hospital, with Lauren describing one hospital ward as dark and dingy and Naomi wondering how she could ever get better in an environment like that. Added to this landscape was the reality that they were being cared for with patients much older than themselves, with cancer at various stages on the cancer journey, with many of them dying. This was experienced by Mick’s first night in hospital when the patient in the bed next to him haemorrhaged and died. Fulvia explained this experience of dying in the adult system as “adolescents in an adult ward is like a death sentence, they rub it in your faces, death and dying” which was not an incentive to get better.

The horror of watching the side effects of treatment was similar with family members in the paediatric and the adult system, with the resultant feelings of hopelessness and helplessness; Shane described the experience as like a roller coaster ride. For some there appeared to be no care plan, as was seen with Sue trying to have Ben admitted to hospital when his drain was leaking and when he experienced pain when the tumour in his back grew over Christmas time.

The problems with communication appeared to be more evident in the adult system, with confused boundaries around who needs to know the information. For example, Mick being told they were going to take out his spleen, his right lung and his eye with no person to support him when he was told this, whilst in Lauren’s story she was the one who knew most of the information.

As with the family members in the paediatric system, all the family members sought to be connected and supportive whilst the AYA was in hospital. Although this appeared to be more difficult to manage in the adult system, due to the life stage of the AYA and the inability of the system to accommodate overnight stays. Arlene was unsure if she could stay with Mathew James overnight because of a sense that she would be judged because of his age and Fulvia had to fight for this privilege. Other carers, such as Marilyn, Rebecca’s mother and Pam, Grant’s mother spent long nights on uncomfortable chairs. Added to this were the sacrifices which all the family members were required to make.
to stay connected and supportive, such as being dislocated from family and friends and having to take time off work.

The AYA’s cancer journey impacted not just on the AYA and the family member, it also had a ripple effect on others who were part of the cancer landscape. For example other family members were required to take on roles to enable members of the family to stay connected and supportive to the AYA. This was seen in Lauren’s story as she took on more of the day-to-day responsibilities so her mother could care for Grant. Partners were also required to accommodate the changed roles associated with the cancer landscape, as was seen with Helen and Geoff ensuring that one of them was with Mick all the time. Geoff was accommodated through work to ensure that he could still maintain his sick leave and continue his role as a father to Mick. This staying connected for Mick placed a strain on the relationship as both Geoff and Helen were required to spend periods apart in order to care for Mick and continue their previous roles.

This new landscape affected also the intimate relationships of the AYA, with Mick’s girlfriend not being able to cope with his cancer journey, whilst Jadye’s boyfriend stayed supportive throughout the journey to the extent that he would stay in hospital overnight, even though this was not expected in the adult system. This is also evident for the friends of the cancer patient with Mick, because of the tyranny of distance, feeling isolated from his friendship group. He sought innovative ways to stay connected to his friends and even managed to increase his friendship group. Ben was supported by his friends throughout the journey with many of them spending time with Ben when he was in the Hospice dying. This is also seen in Irene’s story where his friends stayed connected throughout the journey and lifted him onto the undertaker’s trolley after he died. This is in contrast to Grant whose friends dumped him, Shane believing they couldn’t cope with the cancer landscape.

These stories spoke occasionally of the impact that health care professionals had on the cancer landscape. This impact was both positive and negative. The negative impact was mainly associated with communication, and a lack of respect and awareness of the needs of an AYA cancer patient and their family. This is particularly evident with Jadye when the nurse pulled Jadye’s cannula out and told her to go home. On the other hand, positive impacts were usually associated with the health professional treating the AYA as normal and discussing issues outside of the cancer landscape, as was seen with Mick with the relationship he developed with his counsellor.
As with the paediatric family members, all found the dying hard but were relieved when the AYA died and the suffering was over. Interestingly no AYA who was cared for in the adult system, with the exception of Tamina, died at home. There appeared to be no end of life discussion in relation to choices with respect to dying. As with the AYAs in the paediatric system, the family members were amazed at how the AYA managed the cancer journey with resilience and striving for normality.

Similar to the paediatric core stories, the experience was similar for the parents and the siblings. These reflections on the family members’ core stories of AYAs who were cared for in the adult system, suggest more similarities than differences to those cared for in the paediatric system, although the adult system did not understand the unique needs of these people and found it more difficult to accommodate their care needs.

It is interesting to note that the stories in this study include stories from family members whose AYA died twenty years ago to those whose family member died only twelve months previously. It would be expected that these stories would reflect more differences than commonalities but this did not appear to be the case in this study. All the stories followed a similar trajectory and spoke of similar experiences. In particular; watching the horror of treatment; feeling out of place within the hospital; finding it difficult to circumnavigate the cancer landscape; being amazed at the courage and resilience of the young person; witnessing the dying; and feeling a sense of relief at the end. This suggests that the cancer landscape for AYAs and their families has remained relatively constant over time.

The stories in this chapter have provided insights into the commonalities and difference for the thematic analysis which will be presented in the next two chapters, Chapter Six discussing the themes associated with the Departure, Exploration and Anticipation stage of the cancer journey and Chapter Seven discussing the Destination stage.
CHAPTER SIX: ANALYSIS AND INTERPRETATION

THE META–NARRATIVE: THE CANCER LANDSCAPE

DEPARTURE, EXPLORATION AND ANTICIPATION STAGES

Three wishes for my child.

In this earthly life I would wish for my son a loving partnership that would grow and deepen over a life time, I would wish him the joy and pain of having children share his life; I would wish him to find pride, self expression, and a place for himself in society through work. Yet not one of these wishes is in my power to grant him. He has his own destiny.

There is no mention of health – good health? … The question is a universal one but my answer has come from a time Before Tumour. But isn’t good health part of the natural order of things, my mind protests. Charlie only ever wanted – I only ever wanted for him the natural order of things.

(Addison, 2001, p. 82)

INTRODUCTION

Chapter five provided the reader with four complete core stories and reflections of the other core stories of the family members in this study. Within these core stories there were many commonalities and some differences in the experiences of the family members. This chapter presents the analysis and interpretation of the family members’ stories in order to create a meta-narrative. The interpretation of the stories and the creation of the meta-narrative provides a deeper understanding of the meaning of these experiences. The creation of the meta-narrative occurs through the identification of the commonalities and differences in the themes and subthemes identified in the family members’ stories. Within this study overall, 23 themes and 69 subthemes were identified.

The meta-narrative of these themes and subthemes is created through the process of configuration, in which themes and subthemes from the family member’s stories are
temporarily emplotted to form a beginning, middle and end. A narrative framework was
developed to assist in this emplottment and the creation of the narratives.

Initially, as discussed in Chapter Four, it was thought that the illness narratives
described by Frank (1997) would provide some framework for the interpretation of the
stories. Some of themes could be interpreted through the restitution, chaos and quest
narratives. The illness narratives in this study did result in a sense of restitution if family
members sensed a reprieve from the cancer journey. The quest narrative was also
evident with the resilience of the AYA and the family members, although for the AYA
there was no boon as they did not complete the hero’s journey. From the author’s
interpretation, the family members were always living the chaos narrative and still
struggling to understand the ever changing cancer landscape and the journey they had
travelled and were continuing to endure. In addition the narratives speak of place and
space, as the family members enter a different landscape associated with the cancer
journey.

So, in order to provide a framework for the meta-narrative of this study the themes and
subthemes were emplotted using Armstrong-Coster’s (2004) four stages - Departure,
Exploration, Anticipation and Destination, which provide a temporal structure for the
cancer journey. The four stages were identified in Chapter Four as turning points in the
family members’ stories. There are four themes within the Departure stage, six within
the Exploration stage, one within the Anticipation stage and 12 within the Destination
stage. The themes associated with Departure, Exploration and Anticipation of the cancer
journey, the number of stories in which the themes were identified, and the number of
references to the theme that occurred in all the stories, are detailed in Table 6.1. This
table also includes 35 subthemes emerging from the themes, which provided a deeper
understanding of the experience for the family members, and also listed. (The table has
been laminated and placed in a folder at the back of Volume 1 of this thesis as a quick
reference for the reader).

The subthemes within these themes were identified as elements of the theme which
provided a deeper understanding of the experience for the family members. The themes
and subthemes for the first three stages are presented and accompanied by example
quotes from the family members’ stories. An overall reflection on the themes and
subthemes in each stage is presented before moving onto the next stage. These
reflections provide insight into the experience of family members as they negotiate the cancer landscape with the AYA.

The Destination stage is discussed in Chapter Seven as the analysis and interpretation of these stories provided a different meta-narrative of the dying landscape, as the family members’ stories moved on from accepting the horror of treatment and a possible cure, to acknowledging that death was probable and how to deal with this.

**Entering the Cancer Landscape**

Susan Sontag in her classic investigation into the metaphoric meaning of illness commenced her critique with the following words:

> Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (1991, p. 3)

The family members and the AYAs in this study have all had citizenship in the kingdom of the sick. This citizenship confines the AYA and the family members to a landscape in which place and space is associated with the care of an AYA with cancer. Susan Addison (2001) in her story about her son Charlie dying of a brain tumour, talks of the natural order of things, the familiar landscape in which children outlive their parents. She says behind this façade of the natural order of things is an unfamiliar landscape we are fearful of entering. The family members in this study, despite the fear, were required to enter the unfamiliar landscape of living with and dying from cancer.

**Departure**

*Why was I so sure that nothing could go wrong when here I am standing here singing a new song* (Anthony Barling, 2001)

The stories in this study of noticing that something is not quite right to the actual diagnosis all have a similar plot. Once confronted with the diagnosis, the families had an immediate initiation into the cancer journey and entered the unfamiliar cancer landscape.
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Table 6.1 The Cancer Landscape: Themes and Subthemes
This initiation and entering into the cancer landscape begins when it is noticed that something is wrong, through to the procedures and tests to confirm what is wrong, followed by the reality that the AYA has cancer and could die; However for some, it was not clear whether their family member had cancer due to confusion about what cancer is.

The following four themes were identified within the departure stage of the family members’ stories: something not quite right, confirming what’s wrong, being confronted with the diagnosis, and response to diagnosis.

**Theme: Something Not Quite Right**

The commencement of this initiation is the family members’ response to the initial sense that something was wrong. This initial sense that something was not normal was not usually interpreted by the family members as being anything serious to worry about although, they all suggested or went with the AYA to seek medical advice or opinion. The subthemes associated with the theme *something not quite right* included noticing something different, detecting symptoms, and the family members’ response to the symptoms. These triggers or subthemes were not mutually exclusive, with triggers overlapping with some of the family members.

**Noticing Something Different**

Mick had always been fit and healthy and had not been to a doctor much. When he noticed a lump his mother Helen thought it was nothing to worry about, but if he was concerned she suggested going to the doctor:

> he kept saying he had this lump there and I was saying, oh it’s just a blind pimple or you know, and you’ve cut it when you’ve been shaving or whatever. And then it was still there in about four days and I said, Mick if you’re really worried take yourself off [to your] Doctor (Helen).

On the other hand Denise noticed something was different with Brenton James’ eye turning in. Brenton James being a teenager refused to acknowledge that there was something wrong:

> Brenton James was 15 at the time and ... and started to have his left eye turn in and I just started to notice it was a bit strange at the time and I asked him
what was wrong with his eye and he got quite cranky as teenagers do, and said, nothing, there’s nothing wrong with my eye. You’re as bad as the kids at school, they’re asking me that. I said, well mate, your eye is turning in and something’s wrong with it.

Whilst with Arlene there were no obvious symptoms and noticing something was different was Mathew James appeared to be tired and withdrawing from activities. She rationalised why he was tired given his life stage although there was always a thought in the back of her mind that things were not right:

… as I said, he had his Year 10 graduation and he looked fine but … But then, the summer when he was 15, he said to me, Mum this summer I’ll just play cricket and nothing else … And, he just sat around a lot … and I thought well, you get tired in year 10. They’re worn out, they’ve got the band, they’ve got exams, but something in the back of my mind just niggled, as it does when you’re a mother.

**Detecting Symptoms**

Denise knew Brenton James’s eye was turning in and she knew this was serious when they discovered he couldn’t see out of his eye:

and then that night I asked him to cover his right eye and tell me what was written on a piece of paper, and he said … Mum I can’t see anything. And I said, well how long has it been like that, and he said, I don’t know, I didn’t know it was like that.

**Health System’s Response to Symptoms**

With all of the family members in this study, it was the family member or the AYA that noticed that something was not quite right and sought the opinion of a medical doctor to confirm what was wrong. For 12 of these 20 family members the medical doctor immediately referred the AYA for diagnostic tests to confirm what was wrong. For the remaining 8 of the 20 family members the doctor did not initially suspect cancer and did not refer the AYA for diagnostic tests until it became obvious that there was no alternative explanation for the symptoms, the symptoms did not respond to treatment, or
at the insistence of the family member. Cameron, Geoff and Sue’s stories give us examples of the system’s slow response to the symptoms.

Cameron recalls the system’s slow response to Kristie’s lump on the side of her hand. It was only when his Mum went to the hospital with Kristie and insisted she have tests that she was finally diagnosed:

> it just started off as a lump and, being unaware of cancer we had no idea it was going to turn the way it did, so we all thought it was a lump it would go away … it started off, like I said small then grew, and we went to about five doctors and they all said the same thing it is just a lump, a cyst … and it will go away. And it wasn’t until mum had sort of had enough of the fifth doctor saying the same thing, she actually went to hospital and said there is something seriously wrong and got her into the tests and stuff and that’s how we found out it became Rhabdomysarcoma.

At first Geoff found the system slow to respond. They tested for different conditions because a boy in Mick’s condition who was young, fit and healthy wouldn’t be expected to have such a fast acting cancer. After the tests had been exhausted he was referred to an oncologist:

> we found the system initially, was a bit slow to react to his symptoms, and what happened was, they said “oh well, you know, we’ll just book him in to have a biopsy on it” and they did some blood tests … there was no real urgency in it and I really didn’t understand that because … originally we were looking for what these symptoms might’ve been and you start gathering information and you never think that a boy in his condition would be … diagnosed with such a terminal, fast acting condition, and we had all these theories … it got to the stage where … they said … “we’re going to refer this on to an oncologist … and a surgeon so that we can get these inflamed lymph nodes out and actually do a biopsy on it and find out what’s going on.”

Life was busy for Ben, and Sue found it difficult to find the time to get him to the doctor. Self-blame was an aspect of her response because they waited so long to seek a possible diagnosis:
well Ben was out doing things, he didn’t stop that whole time … one night he said, “Mum look at this, it’s itchy and it’s bleeding.” I said, “okay we’ll go back to the doctor” … well by that time I was really worried … and of course, now I blame myself … because we waited so long to go to the doctor, and every time I said to “Ben, we’re going to the doctor” [he said]. “Oh I can’t today I’ve got this on or that on,” so … I had to practically sit on him to get him to go.

**THEME: CONFIRMING WHAT’S WRONG**

The theme confirming what’s wrong related to the diagnostic tests and procedures, which were done in response to the AYA symptoms, and confirmed the diagnosis of cancer. Deborah, Denise, Fulvia and Lauren’s stories all speak of the definitive step into the cancer landscape as they are confronted with the reality of the diagnosis of cancer. These steps into the cancer landscape were associated with being initiated into the pain and dislocation from home often associated with the cancer journey.

Deborah remembers finding a lump on Matthew Anthony’s leg. After the surgery to remove the lump she intuitively knew that something was terribly wrong:

_...and then it was about a week after the surgery … and … by that stage I was starting to think something’s not right. I just had that gut feeling that something was terribly wrong and when the surgeon rang me up and said, “we’ve got the results in can you come in and see me,” he might as well have told me over the phone because that was pretty obvious._

This is highlighted by Denise, when confirming Brenton James’s melanoma. This resulted in a trip to Melbourne away from home for definitive tests:

_...and they said to me that he had a growth or a tumour or something in his eye and that he would have to go straight away to the Eye and Ear hospital in Melbourne … there were two eye specialists … and they said to us that they were pretty sure that it was a melanoma, and that they would do further tests, but they thought he would lose his eye._
This definitive step into the cancer landscape with the confirmation of the diagnosis was often accompanied by painful procedures and an introduction to the feeling of helplessness that accompanies the cancer journey. This is reflected in Fulvia and Lauren’s stories.

Fulvia gives a graphic description of the painful and messy biopsy. This biopsy, like Denise’s confirmation, occurred away from home:

_We went to Sydney … they did a biopsy in the worst spot ever, which may’ve caused even more pain and it was hell and the tumour was trying to come out through where they’d done the biopsy and they just made a mess of her and they still didn’t know what it was._

Lauren also spoke of the horrible nose biopsy her brother Grant had in order to confirm the diagnosis. The sight of Grant’s physical state and the non-confirmed diagnosis was distressing to both Lauren and Grant:

_so, I got to the hospital and he had had a biopsy through his nose, so his nose was bleeding … It was horrible. He was … leaning over like the kidney dish and the blood was just coming out and I think he was in shock, and he was really emotional and Mum was emotional. It was horrible … not knowing what it was._

**Theme:** *Being Confronted With the Diagnosis*

The theme being confronted with the diagnosis is the way that the family members were informed that their AYA family member had cancer. Family members’ stories included, the way they were told, initial confusion about the diagnosis and being confronted with the reality of treatment and possible death.

*The Way They Were Told*
There were mixed stories, both positive and negative, on the way the family members were told. The stories demonstrate that the way the AYA and the family members were told influenced how they perceived the cancer and how they entered the cancer landscape.

Deborah thought the way they were told was very positive and informative:

> I took Matthew (Anthony) in … and the doctor was really good, he had a nurse in there with a box of tissues, it was really good. [They] … had some little pamphlets and a few little things for Matthew (Anthony) with phone numbers for the Kids Help Line and CanTeen and Challenge and things like that, that would possibly help him.

This is in contrast to Josephine who said the language used by the doctor was clinical and focused on the forthcoming treatment and a possible geographical move:

> after the CT scan the surgeon came and saw me and (my separated husband) and he said “it’s Ewings sarcoma he’s going to have his leg amputated at the hip. We can’t do the treatment in Canberra you’re going to have to move to Sydney because you’ll be up there during his (chemotherapy) treatment, oh and he’ll have to be on crutches from now on because he’ll get a fracture in that femur if he falls over” … Christopher was teary, I was stunned, Paul (his father) just sat there … so that’s how we ended up with the first diagnosis.

**Initial Confusion**

For others there was confusion about the actual diagnosis of cancer and this was related to a lack of knowledge and information provided to the family members at the time. For example, Trish whose brother Paul Vincent was diagnosed with leukaemia did not understand that leukaemia was cancer:

> to be honest leukaemia wasn't a big thing … didn't know much about cancer and so I probably thought deep down it is curable … because, well
... part of you thinks oh well … to me cancer means they are going to die but leukaemia is a different word to the cancer word so I was fairly positive that he was going to live.

With Kerry there was a similar reaction with confusion about cancer and a tumour and a lack of confidence to clarify the diagnosis:

I didn’t even know if that tumour was cancer … I’m … thinking well what do I say and do, I don’t know. I didn’t even know what a tumour was, you hear cancer … you don’t know it’s one and the same … I didn’t know whether to ask if it was cancer.

**Being Confronted with the Reality of Treatment and Possible Death**

For others the diagnosis was accompanied by the reality of treatment and the possibility of death.

As is seen in Deborah’s story, after the doctors had done all the diagnostic tests they were told Matthew Anthony’s chances were poor but they would try:

the doctors really didn’t say very much to us, just that it was confirmed that it was a very rare type of cancer … he had all the tests and then they sat us down about 5 days later … and told us pretty much that his prognosis was not good at all, he’ll be very lucky to survive this cancer, but they’re gonna give it their best shot.

**Theme: Response to Diagnosis**

The confirmation of the diagnosis of cancer induced a variety of emotions for the family members in this study. These emotions are reflected in the present theme; response to diagnosis. The range of emotions varied from shock, to thinking it was the worst thing, to just accepting it, to tears, to exhaustion, and relief.

When Fulvia, her best friend and Jadye were told of the diagnosis they were all in shock:
we walked out of there and my best friend was with me, and she just said to me, “don’t fall apart … don’t do this in front of Jadye … be strong …” Jadye [said] “what’s going on?” … we all were in shock.

Lauren responded to the diagnosis with tears because of how vulnerable and troubled Grant was:

I remember going out into the hallway to cry because I didn’t want to cry in front of Grant … he was so … vulnerable … troubled I think is probably the word. So that was all pretty crazy.

Kerry can’t remember much. She does remember feeling exhausted and thinking Alinta would die:

Alinta … was not very well, getting worse by the minute … and some of it I can’t even remember. I remember it in my head … I can see all the pictures there but it’s very hard to actually say everything … I thought she would die … and you have no sleep, you’re exhausted.

While Cameron didn’t really understand what was going on and just accepted it:

and the first thing was … we’ve got this problem. I was more unaware of it, well being a kid I just thought it would go away … because[at] 14 … you don’t really have a good grasp of what is going on you just accept what is happening and you go with it.

Whilst Cameron’s response was in relation to a lack of understanding of the severity of the cancer, Val (mother of Susie) and Tania (sister of Susie) both spoke of it not being a big shock because of the expectation that she would eventually be diagnosed with leukaemia. Val was surprised at Susie’s relief when she was diagnosed:

for … nearly ten years … we’d known it was going to happen, so it wasn’t like a big shock … I mean … you didn’t want it to happen but it wasn’t a big shock to us … It was more like, okay now it’s happening, so where do you go from here. (Tania)
She (Susie) was relieved when it did happen. I was probably a little bit surprised at actually how relieved she was … and I had a pretty open relationship and talked about everything and I don’t think I really knew the exact depth of her concern as to when she was going to get it … it was quite surprising, the relief she showed when she was actually diagnosed. (Val)

**Reflection on the Departure Stage**

The Departure stage for the family members in this study is the commencement of the cancer journey and entering into the unfamiliar cancer landscape. The family members until this point in time have been travelling a familiar landscape, with an expectation of the natural order of things. The first Theme of the Departure stage *something not quite right* sees the family members sensing that things are not quite as they should be. This initial sense was usually interpreted by the family members, or the AYA, as not being anything serious to worry about. Despite this they all suggested, or went with the AYA, to seek medical advice or opinion when it was obvious that things weren’t normal. This initial lack of alarm when the family members sensed that something was not as it should be has been suggested in the literature as a consequence of the life stage of the AYA and the AYA’s family.

As mentioned by Addison (2001) the natural order of things does not include a diagnosis of cancer for an AYA as good health is the natural order of things. The AYAs in this study were all active and healthy; the reality of a diagnosis of cancer was not in the family members’ frame of reference. Chapter Three suggests life stage issues exclude cancer from the family members’ and AYAs’ frame of reference. This exclusion results in the following behaviour - the AYA’s strong sense of invincibility, which may delay visiting a medical practitioner out of denial or embarrassment (Albritton & Bleyer, 2003). It is also rare for AYAs to have cancer; therefore, symptoms may be attributed to other factors, such as physical exertion, fatigue and stress (Albritton & Bleyer, 2003).

The system’s slow response to the AYAs’ symptoms was told in eight of the stories and was seen in Cameron, Geoff and Sue’s stories, when confirming something is not quite
right. These delays meant that it took longer than expected for the AYA to be diagnosed.

At this stage in the cancer journey the family members are still living with the expectation that they are still part of the familiar landscape and have not yet crossed into the unfamiliar cancer landscape. These stories tend to reinforce what have been hypotheses in the literature that there can be a delay in diagnosis for AYAs with cancer (Miedema, et al., 2006; Pollock, et al., 1991). The literature suggests reasons for the delay are multifaceted and are dependent on the AYA’s life stage and the expectation for the AYA, their family and the health care professional that cancer is not something to be expected within this particular population.(Albritton & Bleyer, 2003; Coscarelli, 2003; Grinyer, 2007a, 2007b; Miedema, et al., 2006). A diagnosis was finally given to Kristie on her presentation to the emergency department which Grinyer (2007b) discovered in her study was predicative of a more rapid diagnosis.

Once the AYA and family members became aware that something was not quite right the stories spoke of how the diagnosis was confirmed and the tests and procedures which the AYA experienced. This confirmation is a turning point in the family members’ stories from being aware that something was not quite right for the AYA to the realisation that something was seriously wrong. This begins the AYAs and the family members entering into the unfamiliar cancer landscape, totally disrupting the natural order of things with little understanding of what is part of this unfamiliar landscape.

For example the confirmation that something was wrong involved tests and procedures, all associated with pain and suffering. For others, to confirm the diagnosis resulted in the AYA and the family member receiving the diagnosis away from family and friends as they travelled to metropolitan areas for the confirmation. This departure from the familiar landscape of the natural order of things is the beginning of what Frank (1997) describes as the chaos narratives that are told as “unmaking the world” (Frank, 1997, p. 103). For the family members in this story their world has been unmade through the diagnosis of cancer. Frank (1997) says chaos stories are hardest to hear because they are threatening and provoke anxiety. Whilst the family members have had time to reflect on the Departure stage and produce a verbal story when living this stage, there was no mediation only chaos. Frank (1997) believes chaos is never transcended and to accept “chaos always remains the story’s background and will continually fade into the
foreground” (p. 110). Essential to the chaos stories is the lack of control of the process and the illness and being “sucked into the undertow of illness and the disasters that attend this” (Frank, 1997, p. 115). The family members in this study have all, with the diagnosis of cancer, been sucked into the cancer landscape. The diagnosis brings the family members into a strange landscape surrounded by confusion and lack of understanding of the experience of what is expected on the journey through this unfamiliar landscape.

From these stories in the diagnosis stage, the initiation into the chaos narrative was related to whether the health care professional respected and understood the chaos, confusion and horror the family members were experiencing as they commenced the cancer journey within this unfamiliar landscape. The way they were told the initial diagnosis made a difference as to how they assimilated and accepted the diagnosis. For some, being confronted with the diagnosis was not just being informed that the AYA had cancer but was overshadowed by the reality of possible death.

Dias, Chabner, Lynch, and Penson (2003) talk about how in the clinical field of oncology, clinicians are forced to break bad news. Bad news is defined as “any information which adversely affects an individual’s view of his or her future” (Buckman, 1992, p. 15). In a case presentation a patient told the Schwartz Center Rounds, (a centre established to promote compassionate health care in the USA) that she was there today “because if only one person hears this story and understands just how traumatic being given a cancer diagnosis is, it will be worth it” (Dias, et al., 2003, p. 589). In the Departure stage of the family member’s stories there was confusion, witnessing horror and for most a lack of empathy in the way the diagnosis of cancer was delivered to the patient and/or family. The way the information was presented made a difference to the way the family members responded to the news. Penson and Slevin (2002) say the essential elements in breaking bad news include: being prepared for what they know and want to know; warning that the news is serious; being simple and clear; checking if the message has been understood; pausing to let the information sink in and responding to their reactions; and establishing a plan for how to move on. Intrinsic to delivering bad news compassionately is “providing emotional support, responding to patient and family reactions, assuaging any fears of provider abandonment, participating in group decision making, and maintaining a sense of hope” (Dias, et al 2003, p. 593). Dias et al (2002, p. 595) concluded “the way in which oncologists elicit and impart
information contribute to the quality of patient treatment.” For Josephine this empathic way of breaking bad news did not appear to be followed. Other stories in this study tend to confirm this. Although Deborah relates how the news was given with compassion and care and in a way it could be understood.

Following on from this, the response to this confirmation of the diagnosis being cancer was varied among the family members. This varied response to the diagnosis confirms the individual differences in the way people depart from the previous landscape and enter the cancer landscape. This highlights that there is no predictable response to a cancer diagnosis and further emphasises the importance of health care professionals responding in a compassionate and empathetic way, which respects the individual differences of the AYA and the family members’ response to the diagnosis.

Summary: Departure Stage

The Departure stage of the journey into the cancer landscape for the family members in this story commences when something is seen as not quite right. At the time there is no concern and panic given the unspecific signs and symptoms, the health of the AYA and the expectation that young people don’t get cancer. This was seen in some cases by a delay in diagnosis with a health system slow to respond to the symptoms. Confirming the diagnosis of cancer was the first step of crossing the threshold into the unfamiliar cancer landscape that involved procedures and, for some, painful biopsies. Once the cancer was confirmed the way they were told made a difference to how they assimilated the information. For some there was confusion as to whether the AYA had cancer or not, whilst for others they were confronted with the reality that the AYA could possibly die. As can be expected, the family members responded to the diagnosis with various emotions such as shock, tears, exhaustion, acceptance and relief. This is the first stage of the cancer journey and the family member and AYA are now required to explore the cancer landscape with their limited experience and knowledge.

Exploration

Lost in a storm preaching to the sky for mercy (Anthony Barling, 2001)
Once the diagnosis has been confirmed, the treatment or Exploration stage of the cancer journey begins. The Exploratoration stage sees the family members viewing the landscapes in front of them and preparing to explore the unknown. The Exploration stage of the family members’ stories proved to be the major stage with a total of 784 references. The majority of the references were in connection to the hospital experience (225), the effects of treatment (114), supporting the AYA though the experience of treatment and hospitalization (107) and how the AYA managed the cancer journey (71). The analysis identified seven themes: being informed about treatment, the reality of hospitalisation, watching the inevitability of treatment, staying connected and supportive, recalling what helped, living the quest, and sensing a reprieve.

**Theme: Being Informed About Treatment**

The initiation into the Exploratoration stage involved the establishment of family members’ and AYAs’ communication patterns with the health care professionals concerning treatment and treatment options; this also included how care was communicated. Similar to the Departure stage of this study, the family members had some difficulty with how they were informed. The stories spoke of the lack of understanding of the information, not enough information, to whom the information was told, the way the information was given and problems associated with communicating the information.

**Lack of Understanding of the Information**

Helen did not understand the medical information provided, which resulted in Mick not being capable of making decisions:

> everyday we feel like you’re … bombarded by information … The medical thing … until you go through it you really don’t know what questions you should’ve asked … with Mick … he just wasn’t capable of making all the decisions … he really didn’t understand because we didn’t completely understand.
Val has a similar story saying it was difficult for Anthony Charles to question a health professional when he didn’t understand:

_he was a kid in an adult world and for him, things were explained to him in an adult way … But he didn’t feel that he had the right to question what was being told to him by a professor or a nurse or whatever and whether or not he understood it didn’t really matter._

In contrast, to Helen and Val, Fulvia (who is a nurse) interpreted the medical terminology for Jadye because she was connected and understood Jadye:

_they weren’t dealing with Jadye they were dealing with me and … they would try and speak to Jadye in all this medical terminology and I’d [say] no Jadye, it’s actually like this … I know Jadye and I know how to speak to her and I know what she understands and what she doesn’t._

**Not Enough Information**

Kerry wanted to make the best decision for her family and because of the lack of information provided by health care professionals, lack of access to further information sources and the medical terminology used, she felt ill informed:

_I guess in all fields they tell you what they think you need to know and you don’t have a choice … there’s more information and you’re not told it … They just use these words … and you’re supposed to actually understand and remember what they said and make a rational decision … I’m in a hospital, I have no access to anything, to have someone tell me more and make the best decision for my family._

Arlene wanted to read Mathew James’ lab results because she could understand them better if they were not paraphrased:

_I always wanted to read his lab results … We had this stand up fight every time because I would say … I’m a visual person. I wanted to read in black and white exactly what was said. I didn’t want it paraphrased. I could picture it more I could understand it more if I read._

**Who was Told**
Lauren and Alan’s stories speak of who was told the information. Lauren felt burdened with responsibility when only she, her father and stepmother were provided with the information of some of the major side effects in treatment. Grant and her mother were excluded from this discussion:

*Grant and Mum went outside. Then he took Dad and Andrea (stepmother) and I in … told us the real story and he said “if he has radiation he could lose his vision and he could have seizures” … all the kind of side effects … I guess as a professional he thought that Mum and Grant couldn’t handle it at that point in time … and so from that point, [it was the] start of me feeling … burdened by the responsibility that everyone put on.*

This is similar to Alan’s story where the doctor also determined who was told the information about the complications associated with treatment. The doctor would not talk directly to Naomi:

*but Naomi also didn’t like him because he wouldn’t talk to her directly. She was a young adult, in the eyes of the law she was 18, she was an adult … he kept addressing us and at one stage he made a comment about complications and Naomi asked him “what complications”, and his comment was, “Oh look you don’t need to talk about that at the moment. If it happens down the track well then we’ll look at it”.*

This is a different experience for Helen where she was excluded from the information. She believes (Mick) didn’t really understand but he was told because of his age:

*because of his age they would talk to him, which was logical and right, talk to him about things when I wasn’t there and if he was on different doses of different medications he didn’t really understand what they were saying, he just trusted completely in them, he didn’t ask questions. … But I couldn’t say I want to be there every time you come in and say something because he was nearly 21.*

Helen’s story resonates with Pam’s recollection of how Tamina, was on her own in intensive care when told that she had relapsed even though Pam had asked to be present.
she was on her own. I walked in just after they'd told her … I asked one of the doctors about the results … [and] said, “can you make sure that I’m there” … they got there before me and they’d already told her … she was upset.

**REFLECTION ON BEING INFORMED ABOUT TREATMENT**

Once the family members have been told of the cancer diagnosis the next stage of the journey is being informed about what is involved with treatment. The family members and the AYA are dependent on health care professionals communicating with them the cancer landscape. With an understanding of the landscape the family members and AYAs are in a better position to explore and understand the landscape. It was difficult at times to interpret the map due to problems with how, how much and to whom the information was communicated.

For example, the unfamiliar cancer landscape was difficult to understand because of the medical terminology and being bombarded with information, which resulted in a lack of ability to ask the right questions and make the right decisions. Some of the information was given directly to the AYAs who felt powerless to ask questions because they did not understand the information. Others understood the information and interpreted this for the AYA, or interpreted the results of tests; however, health care professionals were not comfortable with this.

The lack of understanding was not just in relation to the use of medical terminology, it was also in response to insufficient information on how to enter the cancer landscape and commence the journey. The result was that informed, rational decision making was difficult.

The information was delivered in an ad hoc way with health care professionals choosing whom they believed could be told, based on a possible perceived assessment of who could handle the information. This determination of whom and when to provide information by health care professionals, is confirmed by Good et al (1994) in which the oncologist’s clinical conversation of when to disclose information is determined by the stage of treatment and prognosis. This clinical conversation is usually with the patient rather than the family, the exception is children where alternative narratives are
developed for parents and children. The confusion about who is told in these stories suggested a lack of understanding of the ‘who’ needs to be told in relation to the AYA and the family members. This determination of who is told the information can have unforeseen consequences, such as not being there to support the AYA when bad news is broken, and not understanding the cancer or its treatment through being excluded from the conversation.

Grinyer (2002a, 2004b) provides understanding as to why it may be difficult for the family members and the AYAs in this study to obtain the relevant information to understand the cancer landscape. She suggests that the age of the AYAs creates confusion about who should be told the information. The family members in this study believed it was important that they were present when information was given. At the same time some believed they were excluded from receiving the information, whilst in other stories it is the AYA that is excluded from receiving the information. This confusion is related to the life stage of the AYAs who have, in a sense for some practitioners, achieved adult status and confidentiality should be maintained (Grinyer, 2002a; Grinyer & Thomas, 2001). Whilst for other practitioners there is the belief that the AYA has not yet achieved adult status and they communicate the information to the parent or, in Lauren’s story, the older sibling. These confused boundaries made it difficult for the family members, in this study, as they were unsure of what they need to know and how to ask.

This is despite the fact that literature supports the idea that AYAs want to be provided with honest information, targeted at the developmental stage of the AYA, in order to make informed decisions (Dunsmore & Quine, 1995; Kyngas, et al., 2001; Patterson, et al., 2008a) In addition most want their parents with them when they are informed of treatment and treatment options (Patterson, et al., 2008a). This is compounded by the system in which the AYA is in, as noted in Patterson, Millar and Desille’s (2008) report, which identified that paediatricians and paediatric nurses have limited understanding on how to communicate with AYAs. This inability to communicate with the AYA is further compounded by the paediatric and adult cancer systems evolving independently of each other. As a result of this there are no formal opportunities for training in AYAs’ cancers in Australia (Palmer & Thomas, 2008). This suggests that there is limited understanding of this group of people and their families resulting in difficulties in communication. This lack of understanding was not just in relation to the
use of medical terminology, it was also in response to not having sufficient information on how to negotiate the cancer landscape.

In summary, from this theme, who, how and what is told is based on the medical professional’s perception of who needs to know the information and how much the medical professional believes the patient needs to be told. This is further compounded by the life stage of the AYA and their family.

**THEME: THE REALITY OF HOSPITALISATION**

All the AYAs in this study were admitted to either the paediatric or an adult hospital for treatment. The reality of hospitalisation refers to the family members’ experience of the hospital admission. At this stage the cancer landscape is confined to the boundaries of the hospital and the experiences that are related to this part of the journey. All the stories spoke of this experience, highlighting the impact of this on the family members and the AYA.

The reality of hospitalisation and the associated cancer landscape had various implications for the family members and the AYA, ranging from where the AYA is treated to the practicalities of hospitalisation through to the experience for the AYA and the family members of the hospital stay. This is represented in the following subthemes: place of treatment; hospital environment; response to the hospital experience; social impact; feeling lonely and isolated; problems with communication; waiting; confronting illness and death; not fitting in; isolation from other AYAs; and; lack of understanding.

**Place of Treatment**

For some family members the reality of hospitalisation was influenced by the place where the treatment occurred. The AYAs in this study were treated in the paediatric or the adult hospital, none of which the family members felt were the best places for the AYA.

Irene describes the experience of Thomas having to be in hospital with little kids as terrible:
he was in a ward with kids and it was terrible … they can’t do anything about it, they have to be there, so you just can’t take them home when they’re sick, they have to be in hospital.

This lack of choice with regard to hospitalisation is reflected in Jenny’s story when Brenton Duncan returned as a full on teenager, to the Children’s ward:

we had to come back to the Children's Hospital, because there was nowhere else to go - we couldn’t go to any other hospitals, because there was nothing for teenage children … and by this time he was shaving. He was a real full on teenager.

In contrast Arlene had a choice and asked that Mathew James be treated in the adult system, because of his maturity, with the consequence of not being treated as a family:

I chose the adult ward because he was sixteen with an old head … on young shoulders … a lot older than some other sixteen year olds … but I think that we would’ve been treated more as a family in the paediatric ward than we would’ve been in the adult ward.

**Hospital Environment**

The hospital environment influenced how they experienced the reality of hospitalisation.

Helen was scared by the old hospital wards and had to reassure Mick when she got home safely at night:

at the Hospital, some of those wards we had to walk through to get back to the house, they were scary … they were … basically condemned … when I got back to the house each night I just had to … text him, home, back safe, and then he’d ring me, text me back, love you Mum. He had to know that I got back safe before he could go to sleep.
This is similar to Josephine’s story describing the tumour ward as like a ward from ‘Carry On Doctor’

we ended up in the tumour ward, right on our first night we went to a ward that looked like a ward from Carry On Doctor, there was just rows and rows of beds up and down, they were really old beds, vinyl floor … so that was huge, and the ward was full of old men.

Lauren further confirms the old and dark environment of the hospital ward where Grant first started his treatment:

so they started chemo and Rick (the doctor) wanted him treated at the Royal. It was like the dodgiest ward … and it was like the old, old, old tile house and Grant swore it was haunted it was so, so gross. It was a really dingy ward I think it was dark and just so old.

For Naomi the drab hospital ward made her feel that it was difficult to get well:

she was put into an adult hospital because of her age. The colours were drab khaki green and cream, and Naomi’s comment was, “I don’t really feel like getting well. You wouldn’t feel like getting well in situations like this”, and one of the sisters turned around and said, “Well look at it the other way, the colours make you want to get well to get out of it”.

Geoff sums up the experience of the hospital ward in the following way:

it was ironic … so any young person that is diagnosed with some terminal illness has got to get shipped off either to (a hospital) that was built back in 1800 or 1900 … or some dive somewhere … They’re always patching up old systems or they’re patching up old buildings.

Social Impact

For others the reality of hospitalisation included the impact hospitalisation had on themselves and other family members.

Deborah spoke of the consequences of the time away from her other children and the strain it placed on her mother and sister when Matthew Anthony was having treatment:
and even the other kids, Lauren was 10 at the time and Thomas was 3, Thomas … didn’t like being away from me for a week to ten days at a time and talking on the phone is not enough. Lauren, she’s a very quiet … if you asked her what was wrong she’d always say, nothing, and bottled everything up, and because we were so … absorbed, in caring for Matthew it was unfortunate … that she actually got a little, she got neglected … and very difficult for my Mum as well … My sister was living at home with my Mum at the time … [she] was doing Year 12 … having these two noisy kids in the house … affected her schooling. It just threw everybody’s life out of whack.

For Kerry the social impact was related to the unfamiliarity of the hospital landscape making it difficult for her to parent:

I’ve got two [other] children … and you just live [at the hospital] … So it’s pretty bad … They’re providing a medical service and who does the mothering and the parenting and still making all the decisions in a totally foreign [place], you may as well put me on Mars or somewhere, to try and access the things that I was still supposed to provide as a mother.

Feeling Lonely and Isolated

The subtheme feeling lonely and isolated was in response to the family members’ stories feeling isolated from the support systems they were used to, often because of the need to relocate during hospitalisation, which was sometimes a large distance from the family home.

Denise was lonely and isolated because she was separated from her support network of family and friends:

but I found that it was very, very lonely and difficult for a parent to go through that sort of thing when the people around you are … trying to help you but they’re not part of your inner circle or part of your family … the isolation … having to go down to Melbourne and doing it on my own.

Val has a similar story when talking about Anthony Charles getting his treatment in Perth with the added isolation of not knowing the city:
it was pretty hard and I’d only been in Perth 12 months so I really didn’t know my way around Perth a lot, so having him in hospital … everything was pretty strange. It was a whole new ball game to me … I found it very hard going and sitting in Royal Perth Hospital by myself. I had no friends, no family in Perth.

This loneliness was similar for the AYAs undergoing treatment for their cancer. Helen speaks of Mick’s isolation because it was difficult for his friends to visit. Because of this he felt his friends had forgotten him:

he was a very social person … it was hard for [his friends] to come and visit because most of them were in the same stage as him, just got a car, paying the car off. Maybe just got a job, which was an apprenticeship which didn’t pay much, so to go down there for a weekend, find somewhere to stay [was financially difficult] … He’d sometimes ring his friends at night time if he wanted to talk to them and they’d be going out somewhere, because they were at that age, going out for a barbecue or to a party or down the, whatever and, [he said] “they don’t even think about me Mum, do they?”

Tamina like Mick was isolated from her friends. She was away for seven months and her friends rarely contacted her, which she found hard:

Originally we were told we’d be down there for 6 weeks and ended up being down there for 7 or 8 months … She found it hard … her friends for a while kept writing, and even ringing but that all dwindled off.

Despite this isolation from friends Mick devised ways to stay in touch through internet chat rooms which broadened his circle of friends:

We got him a laptop, which with Mick’s ingenious ways, and a phone card, somehow connected himself to our internet service up here … He actually went onto a few of the chat lines where you meet other people and … broadened his horizon a lot with friends that way … Most nights … he’d be just wanting to get on the internet and chat with his friends … That helped immensely.
The loneliness and isolation did not occur all the time and for some of the AYAs, if a friend was close by, they made every effort where possible to be with the AYA. This is seen with Ben who received his treatment where he lived and his friends cared for him and visited often:

*Ben had a lot of friends … and his friends were just amazing, couldn’t do enough for him. What do you want Ben? Do you want something? Do you want a drink? What can we do? We’ve got to do something, and this is how they were. They wanted to help all the time. … I didn’t know who was coming to see him, any time of the day, of the night. … They’d buy him presents, or chocolates or you know, they’d just come and sit quiet.*

Although, this is not the case for Grant whose friends deserted him as soon as he got cancer:

*Grant only had three or four friends and they dropped off straight away, because I think they wouldn’t know how to deal with it at that age, they were just kids really. I think he had one visit, nice kid … But the others dropped him real quick.*

**Problems with Communication**

The reality of hospitalisation involved communicating and developing relationships with members of the health care team. The family members reported that at times there were problems with communication with some members of the health care team. This was interpreted as a lack of understanding of AYAs and family members, by the health care professionals, and there was a need for more empathic understanding.

This lack of empathic understanding was witnessed by Cheryl in the way the nurses delivered care when they thought Paul Malcolm could not see or hear:

*they weren’t expecting him to be able to see and hear and so they were coming in doing things with him without … talking to him and they would say things over him … There were the sort of things I think, which they would never, ever have said if they’d known he was hearing and seeing.*

This lack of empathic understanding and compassion is confirmed in Fulvia’s story when Jadye was spoken to unkindly when she had had enough of treatment:
She fought it all the way and they’d keep giving her blood transfusions and one day she just said no more, no more blood transfusions … cannulas … and the nurse said, “yeah no worries,” ripped the cannula out of her arm, “go home Jadye, we’re not treating you” … and they were so blasé and uncaring and Jadye had just had enough by then, she’d just been through so much. … and these nurses have never experienced illness, they only know it as a job and it’s sad … no compassion whatsoever.

Kerry also speaks of how unkind the communication was when (the medical specialists) were explaining Alinta’s brain operation without considering Alinta’s feelings:

couldn’t they say, darling you have a glioblastoma, this is what it’s about and this is what we’ll do, or, we’re actually going to operate on your brain.

Couldn’t they change the way they spoke, instead of coming into an efficient manner and calling it the legal thing, a bulk reduction. How mean is that to do that to any person? … There’s no kindness, ever. That we’re a person, that she’s got a brain tumour and everyone’s kind to you in hospital, garbage!

For Helen the problems of communication were not the way she was spoken to or treated - it was the fact that she was ignored:

the thoracic man who used to come and listen to his chest all the time … but doesn’t talk, he listens, whatever he hears he just made the sound, boom boom boom boom. … and then he’d walk out, he didn’t, never talked to you, I’d have to wait for the nurses to come back in to ask what he’d written and he never talked.

Waiting

Family members’ stories in this study regularly refer to the reality of the hospitalisation experience of being patient and waiting for the hospital to provide care and treatment. For Sue the waiting occurred when Ben was in a lot of pain, when his melanoma was spreading. They had to wait to be admitted, only to be told they could not do anything until the next day:
when we went back to the hospital the day after Boxing Day and we waited about six hours and … he was in pain and I went to them several times and explained what had happened and they finally … got him a bed … he was admitted. The young doctor on duty said, “look, we can’t do anything, we have to get hold of the specialist” … and they said they were going to take him and do another CT scan, well we waited there until half past eight … and by this stage we knew we had to go. We had to go out and find a nurse and I said, “what is going on? What are you going to do with my son?” … and she said, “we can’t do anything tonight, you’ll have to wait until tomorrow”.

Rebekah was frustrated because it was difficult get a doctor to come and do a simple procedure and sometimes you could wait all day:

*just getting a doctor up to do it, would just be a nightmare. … There were lots of things that nurses could do but they had to get a doctor up at least to sign off on it first … the doctors don’t have the time and there’s lots of valid reasons why they can’t do it, but … when a patient’s sitting around … whether they’re admitted on a ward or even on the day ward … sometimes you’d be sitting around a whole day for a doctor to come and do a half minute procedure. So it was just oh, it was insane.*

**Confronting Illness and Death**

The reality of the hospital experience was one in which, on a daily basis, the AYAs were confronted with illness and death. Fulvia explained this experience as like a death sentence for an AYA:

*adolescents in an adults ward, it looks like a death sentence. It’s like they rub it in their face, dying, death and dying … it was just not an incentive to get better. It was real dark gloomy, it was a death sentence.*

From Fulvia’s description, it is understandable that this confrontation with illness and death was an aspect that the AYA and the family member found difficult to incorporate into the hospital experience. Some examples of the AYAs’ introduction to illness and death are provided below.
Helen and Geoff talked about the experience of Mick’s first day in hospital where they witnessed the horror of the man in the bed next to Mick having a massive haemorrhage and dying. Geoff speaks of having to stay in hospital for treatment despite the fear of witnessing this horror:

*Mick’s laying there on the bed [and] this fellow started to have a fit and there was blood coming out under the curtain and it was just awful … that was his first day in hospital … that wasn’t a very good introduction. (Helen)*

*Mick had never been to hospital in his life; only to be born … so obviously that had an effect on him. I’d say it scared the living shit out of him, to the point where he’s thinking, well I’ve got to have this treatment … it’s a survival thing there you know. (Geoff)*

Similar to Mick, Rebekah describes Naomi being surrounded by illness and death on her first night making it difficult to believe she could get better.

*One woman was constantly vomiting, and one really old woman constantly couldn’t control her bowels, so it really stank. [Naomi’s said] “how am I going to get well?” I, it was horrible really … you could really see it … all those people you knew … they were there in palliative care.*

The confrontation with illness and death is not confined to the inpatient setting as Arlene recalls Mathew James’ reaction to an old man’s exposed cancer while waiting for radiation therapy.

*I’ll never forget sitting there one day and this quite old man came in with this fungating cancer on his neck, and Mathew (James’) was disgusted. I think it was too real for him, because his was all inside. If he couldn’t see it he could block it out.*

Whilst in the adult system confrontation with illness and death was confined to being surrounded by older people with cancer who were very ill or dying, illness and death is also witnessed in the Children’s Hospital.

Irene describes a young girl who died and finding people dying around you difficult:
there was a teenage girl on the ward. She was actually gorgeous and she had bone cancer in her arm … so she [the mother] put this girl through this reconstruction and she was in absolute agony, but she died actually, she died before Thomas, and it was silly things like that. Watching people dying around you, you know.

Whilst for Jenny this confrontation was Brenton Duncan being aware of possible death when he relapsed:

Then it came back … and that’s when it was much harder, because Brenton was aware of everything, he was 15 [and] he knew [what was going on]. He had seen children die at the hospital.

This confrontation with illness and death is an experience which older adults would find difficult. For the AYAs in this study it was, on many occasions, their first introduction to the reality of hospitalisation and the cancer journey. Compounding this reality of hospitalisation was the family member’s observation that an AYA with cancer did not appear to have a place in the health care system. From the family members’ stories this made the cancer journey more difficult and the reality of hospitalisation even harder to manage. This ‘not fitting in’ was a common subtheme in the family members’ stories.

**Not Fitting In**

Not fitting in to the Children’s hospital was related to the life stage of the AYA and being surrounded by inappropriate activities and behaviours of the children around them. As Deborah observed:

he found that really hard … the Children’s Hospital the second time … one particular time, he was in a ward with all these little kids and they were all watching Thomas the Tank Engine and High 5 and things like that and crying and, and here’s this almost man … he found it really uncomfortable.

This not fitting in was not just confined to the activities and being surrounded by young children on the ward, as Tania described for Susie it also restricted how she could behave and the activities she could engage in:

she hated it. Because they were the majority, were little kids, and obviously with her being 24 when she was in … she’d get really quiet because
obviously there were a lot of little kids and she felt she couldn’t do things that she wanted to, like swearing and all that sort of stuff … the majority of the time she was in a room by herself anyway. She had some of her movies in there, she had the South Park movie and she was constantly having to pause it when the nurses were coming in, because it was not the appropriate movie to have in a kids’ ward.

The inappropriate activities and being surrounded by small children is further augmented by the developmental stages of the AYA. Jenny describes how hard it was for Brenton Duncan when he was admitted to the Children’s Hospital when he was almost a man physically and socially, but there was no other choice:

[When he got the metastases] he was the oldest in the ward and you just felt for him, because there was nobody … his age or to talk to him like a teenager … It was difficult, because there were young children around everywhere in the hospital and he was virtually a man, because he was shaving, he was a grown-up, he was tall, he was nearly 6 foot in height when he died … He was ready to start work, he had part-time work when he was rediagnosed, here we are with little kids … so that was very difficult … but because he’d been through the Children’s Hospital we couldn’t really go anywhere else, because they had the history.

After his initial experience of not fitting in to the Children’s Hospital, Brenton Duncan was referred to the adult outpatient’s unit for radiation therapy. This experience was tempered with sorrow for Jenny as she watched Brent on Duncan question why he was exposed to 80 year olds, when he was just starting to live his life, which made him question why he had cancer.

then we had to have radiotherapy to keep the cancer under control … but it was all old people … they were all old men in wheelchairs … sitting there … you just thought well this is awful to expose a teenager to life with older people … and Brenton would say: “Mum, why me? Why, it’s not fair mum, what have I done wrong to get cancer at my age instead of being old?” … you had no answers … That made it … very very sad and I think that the
staff there knew that but there was no other facility for them to put him we just had to join in with the old people and wait our turn.

Similar to the Children's ward not catering for AYAs, Heather had a similar experience with Paul Vincent in the adult hospital surrounded by men:

well I didn’t like it when he was in the ward with these men, there was one next to him that was nearly dying at one stage, he was in a six bed ward I think and it was pretty awful … it just wasn’t set up for kids, it was just a normal oncology ward in a public hospital …No it certainly wasn’t for teenagers.

Sue speaks of Ben being the youngest in palliative care as there was nowhere else to go:

they never had anyone so young as Ben in there, never … he was the youngest one they’d ever had. That’s the other thing, there’s nowhere for kids with cancer to go.

Val reflected on this ‘not fitting in’ when talking about Anthony’s experience in the health care system:

it’s hard and I mean it’s hard enough as an adult going through adult things in an adult world, without trying to put a kid into an adult world and go through stuff that they’re not ready for.

Isolation from Other AYAs with Cancer

As mentioned previously, the reality of hospitalisation resulted in the AYA and the family members being isolated from family and friends. Not fitting in creates a further dimension to the loneliness and isolation, with other AYAs having little or no other contact with other AYAs who are or have been hospitalised with cancer.

For Fulvia this isolation from other AYAs became obvious when they found the adolescent ward (for AYAs who did not have cancer) where there was a sense of being connected and enjoying other young people’s company:

you know, there was nothing, and then all of a sudden when we found this adolescent ward it had all that, and if she would’ve hung with these people her age, I think they would’ve been more positive … and maybe in a
younger person’s ward they are all special … Even the kids in the adolescent ward when we finally went in there, they were all mingling, they were all laughing and they were all teasing each other and joking and being silly and that’s what she needed.

This sense that young people needed to hang out together, is reinforced by Geoff when speaking about Mick’s hospital stay when he observed how important it was for other young people to be together:

if there was anyone in the hospital that was a young sort of person, they’re all drawn to each other … they hang out in each other’s rooms, they get on the computers and they do stuff on computers … and they were always going into each other’s room and hanging out together, or trying to … you could see it when they walked in there and [no] younger people were in there … they didn’t want to be there unless they could relate to other younger people.

Whilst Mick was able to sometimes connect with other AYAs with cancer, for others there was never the opportunity to talk to other young people as with Grant who never found the opportunity to connect with another AYA with cancer:

there was a lad, they were both more or less keen enough to meet each other, just that their treatment and sickness and wellness sort of thing just never seemed to fit, so that made it difficult. But I think they might have been interested to talk to each other if it had been in their own environment.

This isolation was also experienced in the Children’s Hospital as Jenny noted that, while there were younger children with different cancer, there no other teenagers Brenton Duncan could share with:

He was getting older … and he didn’t have much contact with other teenagers, because there didn’t seem to be a lot of teenagers diagnosed with cancer there. They were mainly younger children with leukaemia and other sorts of cancers, but not a lot that were his age. There was nobody that he could bounce off, telling other teenagers what he is going through.
Pam noted that this social isolation was not as problematical for Tamina who, through CanTeen, would have regular hospital visits by the members who provided inspiration because they had all experienced cancer treatment:

*I think CanTeen helped her because they’d come into the Children’s Hospital … and I think that did help her because most of them, if they weren’t as sick then … had been there, done that. They were amazing, amazing … I think all of them we met were an inspiration, all very strong.*

**Lack of Understanding**

Not fitting in to the health care system and either being surrounded by young children or older adults, as well as the isolation from other AYAs, obviously presents problems for both systems of care. The paediatric system being family and child focused and the adult system focusing on the individual. This results in both systems having limited understanding of the issues specific to AYAs and their families.

This is summarised by Fulvia when recounting some of Jadye’s experiences and the system’s lack of understanding of normal teenage behaviour:

*they don’t have an understanding and I just wish that the support from the hospitals was at their [AYA’s] level … well first of all putting her in with older people, putting her in with men. The nurses saying “I’m not taking any more of this Jadye, see ya later”, and taking the cannula out of her arm and sending her home, and I thought … she’s a teenager, she’s rebelling, that’s what they do.*

This lack of the understanding of specific AYA issues is highlighted by the negative response that Deborah and Matthew Anthony received when they mentioned that he wanted to freeze his sperm:

*at one point, someone had suggested to me getting some of his sperm and freezing it ... And I mentioned it to the doctor … She said, “what would you want to do that for?” And I said, “well Matthew really wants to have children.” “Well how can he possibly know that at 17 years of age, that is the most ridiculous thing I’ve ever heard.” She said this in front of Matthew and Matt said “well, I don’t think it’s ridiculous and I don’t care, I want it
done.” And she said, “well we’re an oncology department, we’re not a sperm bank, so it’s not going to happen”.

Geoff summarised the reality of hospitalisation of not fitting in, the isolation from other AYAs and the lack of understanding with the following comment:

*it’s sad to say that all the young people that actually we seen go through anything to do with the oncology wards … they’re so distant from everyone. You know like the bottom line is they’re walking into hospitals where … there’s old people getting maintenance … and some people having palliative care and they’ve got no real advice for these young people.*

**Reflection on the Reality of Hospitalisation**

Once the cancer journey has been explained, all of the AYAs in this study required hospital admission for treatment. This treatment included surgery, chemotherapy, radiation therapy or combinations of two or all three of these. Patterson et al’s (2008a) Report found that the structure of care rated highly as an unmet need for AYAs on or within a year of treatment. The Report supports the stories in this study that revealed that the reality of hospitalisation was one of the major themes. Hospitalisation requires the AYA to be separated and isolated in a space and place that is disconnected from the AYA’s real world. Health geographers emphasise the importance of space and place when interpreting the reality of hospitalisation. Space is the actual geographical location of care and within this space is a sense of place. Place is the meaning that is assigned to a geographical location. “Sense of place connotes the meaning, intention, felt value and significance that individuals and groups give to places” (Gesler, 1992, p. 738). Casey (2003) argues that place needs to be considered as well as space when inquiring into the hospital experience. “Place matters as geographical location and lived experience, as demarcation of space, and as site of meaning creation” (Bender, Clune, & Guruge, 2009, p. 129). Place within this theme of the reality of hospitalisation refers to the hospital space in which health care is delivered, and the meaning the family members and the AYA give to the experience. From this experience the AYAs’ and family members’ sense of place and the structural aspects of the hospital place can be examined (Bender, et al., 2009).
All the AYAs in this study were required to enter and stay in the hospital space as part of the cancer journey, to receive treatment and hopefully through this treatment be cancer free. For the AYAs the hospital space is a closed system in which they are confined and information from the world outside is through family and friends. The health care professionals within this closed system, have intimate knowledge of what occurs within the hospital space and the AYAs are required to submit to the procedures and protocols which are part of this space. For the family members in this study, this experience is enhanced, or not, by the understanding and knowledge of the health care professionals who assisted the young person and the family members in exploring this hospital landscape.

This hospital landscape was influenced by many aspects of the reality of hospitalisation; among these aspects are the space and place of treatment. Both these aspects influenced the family members’ and the AYAs’ response to the reality of hospitalisation. Some of the effects from the reality of hospitalisation and the space of treatment resulted in a place of loneliness and isolation. In addition, the AYA and the family members were introduced into the hospital reality of waiting for care and treatment. This all occurs within a hospital system where the AYAs and the family are confronted with the hospital reality of illness and death. The reality of hospitalisation meant that the AYAs were cared for in two systems of care. For the AYAs in these stories neither system of care accommodated the unique needs associated with AYAs. Consequently, the reality of hospitalisation resulted in the AYA being ‘misplaced’ in the health care system.

This was highlighted by the AYA not fitting in, being surrounded by young children in the paediatric system or old men and women in the adult system. Due to this misplacement in the health care system the stories told of a lack of understanding of how to manage and treat AYAs with cancer. In addition, the AYAs were isolated from other AYAs with cancer. Some of the AYAs in this study had little or no contact with other AYAs with cancer.

The family members in this study were all aware that the AYA required treatment in hospital, either in the paediatric or adult system. There was little choice in where the AYA would be treated with the space of treatment usually being dependent on the AYA’s age or having had previous treatment in one of the hospital systems. For those that did have a choice it was usually as a result of the AYAs’ limbo age of 16 to 18 where they possibly could have been treated in either system. The hospital experience
for the family members varied according to where the AYA was treated. For the family members in this study, the place of treatment was seen as inadequate for the requirements of an AYA with cancer.

This choice, or lack of choice, for the place of treatment resulted in family members having experiences that were related to the actual hospital environment within this space. The hospitals and wards, equipment and internal structures were described as old, dark and dingy and required renovation.

From these descriptions, we are introduced to a sense of place as it relates to the hospital experience particularly for those AYAs treated in the adult cancer landscape. Gesler (1992) introduces the concept of therapeutic landscapes, which include the built environment and the aesthetics of buildings and rooms. He suggests therapeutic landscapes are places that are part of the healing process. Intrinsic to this concept of the therapeutic landscape are landscapes that are not part of the healing process. The family members’ descriptions of the landscape within the adult hospital system suggest that the AYAs and family members in this study experienced a landscape that was far from therapeutic.

Whilst the place of treatment and hospital environment impacted on the AYA and the family members’ cancer journey, the reality of hospitalisations also had social repercussions that included the social impact for the AYA and the family. The AYAs were separated from their normal everyday activities and isolated in the hospital. Also, for some of the family members in this study, the reality of hospitalisation involved the AYA being hospitalised away from the family home. This had a negative social impact for the family members, as they were unable to engage in their normal everyday responsibilities due to the amount of time spent with the AYA and the distance from the family home.

As noted in the previous paragraph, the social repercussion of the reality of hospitalisation was the acknowledgment that they were in an unfamiliar landscape which was difficult to negotiate. Another social repercussion is loneliness and isolation for the family members and AYAs. This was particularly evident in families where hospitalisation and treatment occurred away from the usual social supports. The tyranny of distance, and having to relocate for treatment, confirm that relocation for families is stressful for families in that it disrupts their sense of normalcy and challenges their
ability to cope. This was noted in McGrath and Rogers (2003) study associated with paediatric families.

This isolation is not confined to the family; it also had major ramifications for the AYA who was undergoing treatment in the hospital. This sense of loneliness and isolation is even more pronounced, particularly the isolation from friends. For the family members in this study, this isolation from friends was more pronounced if the AYA was hospitalised away from home or was hospitalised for long periods of time. Hospitalisation away from home could involve large intra or interstate distances. If the AYA was an outgoing social person like Mick, this tyranny of distance was especially difficult. AYAs used specific strategies to deal with this situation such as the use of laptops, the internet and chat lines. This loneliness and isolation varied for those AYAs whose friends lived close, with Ben having his friends staying connected and supportive whereas for Grant his friends ‘dropped’ him.

Isolation from friends for the AYA is significant for the developmental stage of the AYA where developing relationships with peers is important for the individuation process (Holmbeck, 2002). The isolation is a concern as the literature suggests that AYAs with cancer are dependent on existing social networks for support (Miedema, et al., 2007), which is extremely important for the cancer journey (Zebrack, et al., 2010). In addition, perceived social support from family, friends and health care providers was an important predictor of mental health and for alleviating symptoms of distress associated with the cancer journey (Corey, et al., 2008).

The family members and AYAs in this study were dependent on the health care professionals who have intimate knowledge of the hospital cancer landscape. As with the previous themes, when confronted with the diagnosis and being informed about treatment there were communication problems with some of the medical professionals. The family members reported lack of compassion for AYAs and family members and a need for more empathic understanding. These problems of communication suggest a lack of understanding of the developmental stages of AYAs and their families. These stories demonstrate the hospital cancer landscape as one in which the family members are dependent on the understanding of the health care professionals of AYAs specific needs, in order to explore and develop some understanding of the landscape. Without the assistance of the health care professionals they are strangers in a strange land - a land in which health care professionals fail to see the confusion and fear of those who
have no choice but to explore the hospital cancer landscape. Peloquin (1993) calls these practices dehumanising or depersonalising, he health professional fails to see the personal consequences of illness or disability, engages in distancing behaviours that dismiss the patient, harmfully withholds information through silence, uses discouraging words associated with medical terminology, and engages in brusque behaviours through ill considered remarks and the misuse of power (Peloquin 1993). This was also evidenced in Zebrack’s et al (2010) study where the AYAs found the manner in which information was told was inadequate and was delivered in a cold, aloof and patronizing manner.

The place of treatment, hospital environment, social impact, feeling of loneliness and isolation as a consequence of the reality of hospitalisation is further amplified by what happens during the hospital experience. The dependence on the health care professionals to assist the AYA and family members to explore the hospital cancer landscape, requires patience as the AYA and the family members wait for the health care professionals to determine if, when and how they can explore the hospital space as part of their cancer journey. This waiting involves waiting for beds, waiting for treatments, waiting for procedures and waiting for doctors to be available to do procedures. This waiting has been described by patients and carers as “marking time”, in that life is “put on hold” (Mcilfatrick et al, 2006, Mcilfatrick et al 2007).

In Australian culture the hospital cancer landscape is a place associated with illness, suffering and death. As a result of this the AYA and the family members are confronted with the reality of the experience of illness, death and dying. This was particularly evident in the adult system where the majority of the patients were old men or women at the end stages of their life. This exposure to the death, dying and suffering of others was for some AYAs and family members, their first introduction to the hospital cancer landscape. AYAs in the adult system had many experiences of the suffering of others that were foreign to them. The pediatric system also exposed AYAs to death and dying of children. All these experiences increased the AYAs’ awareness of death and dying and their own mortality at a time when most AYAs had not been exposed to their own or others mortality.

As already noted, the AYA was cared for in either of two systems of care: the paediatric or the adult system. Due to their age and different needs of the AYA, family members
reported that this was difficult to deal with because they didn’t appear to fit in either of these systems.

For example, within the paediatric system age appropriate behaviour and recreational activities were restricted and the AYAs had little choice of what kind of experience they were exposed to. The adult system was also difficult with the AYAs exposure to older people near the end of life. The family members were aware there was nowhere else and were acutely aware that both systems were not set up to care for AYAs. This not fitting in was also evident in palliative care with AYAs rarely being cared for in palliative care as demonstrated in Sue’s story.

The two mutually exclusive hospital systems meant that the AYAs undertaking the cancer journey rarely connected with other AYAs on a similar journey. There are other AYAs on the cancer journey but due to the fragmented care, which has been referred to in the literature (CanTeen, 2005; McTiernan, 2003; Thomas, et al., 2006), it is rare that AYAs have the opportunity to relate to other AYAs. The family members’ accounts all emphasised the need for the AYAs to be with other AYAs. The need for AYAs with cancer to talk to other AYAs with cancer has been identified (Kyngas, et al., 2001; Patterson, et al., 2008a). In one study, discussed in the literature review; this support was rated as more important than family and friends (Zebrack, et al., 2006). In addition, adolescents with cancer found the opportunity to talk to other young people with cancer inspiring (Cassano, et al., 2008).

The fragmented care, and the dichotomous choice in the hospital system results in what Phillips (2009) describes as the AYAs being orphaned in the system. It is not surprising that family members and AYAs found some of the health care professionals had limited understanding of the specific needs of AYAs with cancer and their families. This is confirmed by the stories in this study with Geoff summarising this lack of understanding by saying “young people who go through the oncology wards are distant from everyone and they’ve got no real advice for these young people”. This lack of understanding can be explained by the two cancer landscapes in which the AYA and their family are cared for in. The paediatric system has been described as mainly family focused and the adult system disease focused (Ferrari et al., 2010). These two models of care do not cater to the needs of AYAs, being neither children nor adults (Ferrari, et al., 2010).
THEME: WATCHING THE INEVITABILITY OF TREATMENT

Chemopsychology

Dark caped strangers sweep through me

Sent on a mission to kill to survive

Fast growth will cease as work is done

I draw a line and set a standard at the gate

With weak structures rebels rebel

With a closed hand and a raised arm a wall can be built

Body and mind like moon and tide

Soon strangers are light naked friends

(Anthony Barling 2001)

The reality of hospitalisation is a result of the AYA having to submit to treatment and procedures, which are part of the medical process of attempting to destroy the cancer. This was not a pleasant experience for the AYAs or the family members. Most of the family members spoke of the horror of witnessing the side effects and outcomes of treatment. For the majority of the family members in this study, the theme ‘watching the inevitability of treatment’ was an important part of the story. All of the stories referred to the effects of treatment on the AYA with 117 references which overall was the second most referenced theme in this study. This suggests that for the family members telling the story, the effects of treatment was central to the Exploration stage. The family members obviously saw it as important to include the suffering of the AYAs as a result of treatment, as essential to their story. The AYAs in this study had surgery, radiation therapy, chemotherapy or a combination of two or three of these treatments. Three subthemes emerged from watching the inevitability of treatment: the effects of treatment, difficulties associated with treatment and responses associated with treatment.
Effects of Treatment

All the family members mentioned this subtheme in their stories and spoke of the horrible effects of treatment whether it was the side effects of chemotherapy, other procedures, or surgery.

Watching the inevitability of treatment was the hardest time for Fulvia. She found it cruel and it was torture because of the ‘mess’ they made of Jadye:

they made a mistake with the chemo and they didn’t give the relaxer after the chemo, so she ended up with ulcers in her mouth, all the way down into her stomach, but her tongue was like that fat, and half of it broke off and all the ulcers, her tongue was outside her mouth for two weeks. Her jaw was wide open … she lost all her hair, it was just the cruelest thing … and that was torture. That was probably one of the hardest … and then the foot drop … the therapy caused problems with a nerve in the spine where the tumour was, and she got foot drop, she couldn’t walk. She was a mess.

This mess and cruelty is reiterated by Cathie when she watched Paul Vincent’s eyes burning from treatment:

I remember him screaming out, eye cream, eye cream and trying to wet his eyes, and rubbing oh my eyes are burning. He was in pain and they’re going to give him more new treatment and every time they gave it to him it’d burn his eyes … [it] was cruel … [he] looked dreadful.

Watching the inevitability of treatment was not exclusively related to chemotherapy. Kerry recalled how the effects of Alinta’s brain surgery were like a horror movie, which resulted in both of them being fearful:

after [the] surgery … she’s in pain, there’s a lot of swelling … you weren’t allowed to have pain killers. Like you know she’s got this scar from ear to ear, stapled, head bandages … she’s not allowed to sit up. She’s not allowed to go to the toilet … She’s got these blue machines boxes, one’s a spirit level, because her head is not allowed to come up further than this. She’s not allowed to get up because the fluid’s draining from her brain and that would
just terrify us … it’s got to be at a certain level. [it] is like horror movie stuff. So we’re too scared.

**Difficulties Associated with Treatment**

Watching the inevitability of treatment was not just in response to having to passively watch the effects of treatment, intrinsic in this theme was that some of the difficulties were associated with the AYA receiving the treatment.

Deborrah spoke of the painful bone marrow biopsy when Matthew Anthony was only given a local anaesthetic that had little effect and five people had to hold him down:

> a girlfriend … said to me, when he has his biopsy, make them knock him out
> … the doctor … he said “we knock the littlies out but he’s a big boy … we’ll give him a local anaesthetic and he’ll be right”. Well it took 5 of us to pin him down, Matthew’s father was in there, I was in there and they had to call in extra nurses to pin him down. They’d given him midazolam and he’d had his local anaesthetic and it didn’t touch him, and he remembered every bit of it.

For Helen and Geoff the difficulties were associated with the painful procedures that Mick had to endure after he developed a fungal infection (scedosporium) as a result of chemotherapy. This infection affected Mick’s spleen, lung and right eye. Geoff recalled how they took him to surgery and basically cut him open everywhere. In order to save his eyes he was subjected to some painful procedures, he was given a new drug which they could inject straight into the eye; the treatment affected his retina and caused cataracts:

> all the needles affected the retina so they had to then try and laser the retina back on … They were lasering the scars off and they filled it with gas, the eye, to try and bond again, so he had to stay … on his stomach for 3 days and not move … and then it started to come off again so then they injected it with an oil, and then he had to lay on his back for 3 days … that seemed to work … Cataracts started to grow but they lasered them off … he had so many operations on that eye and he did actually get some sight back.
For Rebekah it was the little things like the doctors not taking a little bit more time to find a vein when a cancer patient is already in distress having been exposed to so many cannulas and chemotherapy:

But when the interns would come in or doctors off other wards and they’re so used to rush, rush, rush, you know that when they’re trying to put a cannula in and you’ve got a patient, a cancer patient whose had cannula after cannula and chemo drips and this, that and the other thing and they’re going, can’t find a vein, can’t find a vein and … the patient is already in enough distress … [they should] take 30 seconds longer or let the … nurses do it.

Whilst with Deborah the difficulties were related to not ensuring Mathew James had adequate pain relief when he was having his bone marrow biopsy, for Rebekah it was the doctors not having the patience to find a vein, which caused distress for the patient.

For Sue the difficulties were related to not being able to access appropriate services when Ben’s drain started to leak everywhere at Christmas time. Ben was just patched up, because his doctor was not available. This worried Sue:

when he had the gland done, they had a drain in, it was a terrible thing to see him having[ it] done … He had a drain in and it was the first Christmas and it started to leak and I didn’t know what to do … we went down to emergency and I explained, and so they put him in the paediatric ward … which he wasn’t impressed with … and poor Ben … it was leaking badly, and it was everywhere … I just had all these towels … So the doctor came and patched Ben up a bit, he couldn’t take the drain out because Ben wasn’t his patient, so it was all a bit of a worry.

Responses Associated with Treatment

Watching the suffering associated with treatment and the difficulties associated with the inevitability of treatment resulted in the family members having affective responses to both.

This is evident in Josephine’s story where, because of her lack of understanding of oncology, she was at a loss and unprepared for the side effects of treatment:
I had no experience in oncology whatsoever … I was at a loss … so we spent a week in Children’s hospital for his first lot of treatment, and of course you were fine through the first lot of treatment, obviously the nausea and whatever but, the side effects didn't happen until we got back [home] and .... Nothing prepares you for it, nothing. Nobody could explain to you how bad it is, and he ended up in hospital … with ulcers right through to his anus, it was just horrible. Nothing prepared us for it, nothing.

Val’s experience resonates with Josephine when she speaks about being naïve about the effects of chemotherapy which made it hard for her know how to manage the side effects:

I think anyone’s naïve as to what chemotherapy can do to your body and unless you’re immediately involved with someone’s going through chemo … I don’t think anyone’s actually prepared we’re probably all naïve when it comes to that … it was hard seeing him go through chemotherapy and ulcers in his mouth and dry reaching and being sick all the time and tired and not knowing what I could do to make things better, or make him feel better about what was happening.

Trish and Heather explain watching the inevitability of treatment as very tough and very wearing as they tried to present a positive front:

the last six months maybe after the first month was pretty full on emotionally and physically visiting him in hospital all the time - very tough, very wearing – (Heather): putting on the face … I’d cry and then walk in and say g’day how you going buddy? … it was so hard and then you would collapse afterwards when you got outside it was so hard.(Trish)

Shane and Andrea also describe how tough and wearing watching the inevitability of treatment was. For them not knowing when a crisis could occur due to the chemotherapy was terrible and like a roller coaster ride:

it was a roller coaster ride … because he’d be up and you think oh good everything is going well and then all of a sudden his bloods would be out of whack and he’d be back in hospital … instantly. As soon as his temperature
went out of whack we had to get him in there ... going through ups and downs was terrible ... you are feeling this one minute and feeling that at the next, you think ... how much longer is this going to go on.

On a different note, the response to treatment was more than about not understanding or being able to control the side effects, it was also about the interruption of normal development for the AYA having treatment. For example, Helen believes that for Mick the response was of frustration; because of the cancer he could no longer control or move forward with his life:

I don’t know if it was anger so much more than frustration ... because he was very much in control of his own life. He was working, [had a] car, girlfriend ... He lived at home with Mum and Dad but that was cheaper, but he was very much in control. He’d been going away to surfing competitions around Australia for years with his friends and the fact that he couldn’t control it, things ... he couldn’t make it go away ... it’s just all taken away from him, and he had a really good job, he had a good sporting career, good car ... he’d just started going forward as a young adult.

Cameron has a similar story when he talks about how hard the treatment was for Kristie to the extent that she missed her teenage years and became an adult:

well it takes a huge toll obviously ... The person who is doing it is Kristie so she was going through everything [including] puberty ... so very hard time, very stressful and painful. Kristie was the one who had all the injections, the portacaths, and the chemo so it was hard work but she was a tough young girl and she matured very quickly, she missed her teenage years and went straight to adult.

**Reflection on Effects of Treatment**

Following on from the reality of hospitalisation, all of the family members in this study found it important to share the experience of treatment. The inevitability of treatment saw the family members exploring another aspect of the cancer landscape. This cancer landscape is dominated by the family members witnessing the suffering of the AYA in
response to the treatment for cancer. Most of the AYAs in this study were treated aggressively with chemotherapy for their cancer, mainly because of their age and the types of cancer they had been diagnosed with. This resulted in many of them experiencing horrible side effects over which the AYA and the family member had little control. The physical effects included ulcers in the mouth, anus, and other parts of the gastrointestinal system, bleeding from orifices, burning eyes, burning in other parts of the body, foot drop, losing sensation in the feet and hands, losing hair, spiking temperatures, nausea, vomiting, fatigue and pain. These effects were described as cruel and in one story as torture. They all found witnessing this suffering hard. In addition to submitting to chemotherapy, many of the AYAs also had surgery to remove the cancer. Some of the surgery involved removing limbs, eyes, body organs, a tumour and surrounding tissue. Family members description of this experience include terrifying, scary and like a horror movie.

From the descriptions of the effects of treatment it is feasible to hypothesise that there would be difficulties associated with this treatment. The stories spoke of these difficulties and how they made watching the inevitability of treatment even harder to witness. Pain and fear associated with treatment was a common thread as reflected in Deborah, Helen and Geoff and Rebekah’s accounts. These accounts speak not only of difficulties encountered with the unexpected results of treatment but also difficulties associated with the everyday management of treatment.

For some the difficulties associated with treatment were a direct response of not being able to understand the cancer landscape, as they had not been provided with a map that contained this information. This resulted in not having enough information to know where to go in the event of unexpected effects of treatment, as seen in Sue’s story.

The last two subthemes have focused on the actual treatments and difficulties associated with the inevitability of treatment. The accounts of these two subthemes demonstrate the horror, the pain and the trials and tribulations of witnessing treatment and accessing appropriate services. Exploring the cancer landscape required a lot of determination and courage as the family members witnessed, and the AYA endured the consequences of cancer treatment. For all the family members, exploring the cancer landscape was hard, exhausting and there was a sense of not being in control, powerlessness and helplessness. This resulted for some in a feeling of being overwhelmed, and not prepared for the cancer journey.
These responses to treatment are emotions strongly associated with the chaos narrative. The chaos narrative as mentioned previously in this chapter, is associated with a lack of control of the process and the illness. The voice of chaos can only be identified and reconstructed. “In the chaos narratives, troubles go all the way down to the bottomless depths. What can be told only begins to suggest what is wrong” (Frank, 1997, p. 90). Frank (1997) describes the suffering within the chaos narrative as not being orderly with the person finding no purpose in the suffering. All the family members in this study were overwhelmed by passively watching the inevitability of treatment with the resultant effects, difficulties and inability to control what is happening. This lack of control resulted in the family members’ describing the inevitability of treatment as hard, emotionally and physically exhausting, like a roller coaster ride, feeling unprepared for treatment and finding it difficult as they were powerless and felt helpless in their ability to alleviate the suffering.

This powerlessness and helplessness to control the effects of treatment meant the AYA had to put on hold normal developmental milestones with feelings of frustration due to the lack of control.

Suffering has been acknowledged as part of the child and adolescent cancer journey. This suffering has personified with the following meaning: cancer is threatening, numbing, uncontrollable and unruly, painful and uncertain (Woodgate, 2008); all experiences which can be identified in this current theme. For the family members witnessing this suffering there was evidence of their own internal suffering as identified in their chaos narrative. The impact of witnessing this suffering and feeling powerless to control the suffering has the potential to result in psychological distress. The literature supports this possibility (Kazak, et al., 2004; Kazak, et al., 2005; Neville, 2005) identifying PTSD and PTSS as prominent for family members who have witnessed a child or adolescent experiencing the cancer journey. There is also evidence as described in Chapter Two of this study that the cancer journey and its accompanying treatment can interfere with the developmental progressions for AYAs (Carlsson, et al., 2008; Epstein, et al., 2004; Mathieson & Stam, 1995; Neville, 2005; Ritchie, 1992; Zebrack & Walsh-Burke, 2004).

**Theme:** Staying Connected and Supportive
Given the powerlessness and lack of control associated with the reality of hospitalisation and the inevitability of treatment, family members in this study attempted to alleviate this suffering and have some control of the process by staying connected and supportive during the AYA’s hospital stay and throughout treatment. Staying connected and supportive was the way the family members in this study stayed involved with the AYAs care both physically and emotionally. This was another major theme within the family members’ stories. All of the stories spoke of how and why they supported the AYA through their treatment and hospitalisation with a total of 107 references; it was the third most referenced theme. This included strengthening existing relationship, sharing the unspoken, being there, being involved with care and keeping a watch. This staying connected and supportive created a sense that the family member could find some positives within this often negative foreign cancer landscape.

**Strengthening Existing Relationships**

The diagnosis and treatment of cancer resulted in the AYA becoming more physically and emotionally dependant on those around them. This is spoken about by Arlene when she describes how she was needed more than usual and her previous relationship with Mathew James was maintained:

> a lot of mothers and sons have that relationship but because of his illness it went on until he was twenty. The apron strings were never cut … because he needed me more intensely and for longer than teenagers usually do.

This relationship between parents and the AYA is further highlighted by Deborah, when speaking of her strong bond with Matthew Anthony:

> we always did have a very, very strong bond the two of us. We’re probably what a lot of people refer to as being soulmates, he and I were one … I knew what he was thinking, he knew what I was thinking. I think I probably, the sort of thing that a lot of twins would have, we were sort of nearly as close as that.

**Sharing the Unspoken**
The diagnosis of cancer and the associated treatments was a catalyst for many of the family members not just strengthening the bonds they shared, but also the family members had the opportunity to share what previously would be kept hidden or not discussed.

For example, Deborah spoke of how Matthew Anthony’s diagnosis of cancer resulted in them having a more open and honest relationship, and promising there would be no more secrets about what was happening to him in treatment:

you can only hide so much and one day he said to me, I know you’re keeping
a secret from me … This is my body, it’s me that’s sick and I have a right to
know, and I really thought about that and I thought well he’s right … and
so I sat down with him and I told him everything and he took it really, really
well. And he … made me promise that there would be no more secrets.

This open relationship developed between and Deborah and Matthew Anthony extended into them being able to have open discussions about death:

We had a lot of talks about death and what happens to a person after they die
… Matthew would ask me questions … what do you think happens to
people when they die Mum? what’s going to happen to me … if I die? am I
going to die? and so we had really open discussions about death. It just sort
of continued, the openness, we became more open about it when he got sick
the second time.

This is reinforced by Val who believes that the most important aspect of the cancer journey is openness between a parent and a child:

openness between the child and the parent, no matter how young or old the
child is, is probably the most important aspect of it as far as I’m concerned.

In contrast to Deborah and Val, Jenny found this open relationship and sharing the unspoken difficult for her and Brenton Duncan. She knew everything about his intimate details because there was no one else to talk to:

Also … sexuality there was nobody for him to talk to … he used me as his
sounding board for practically everything. I think we grew so close, about
dying, he talked to me, and he didn't talk to a psychologist or anybody like
that. He talked to me about his fears, the way he felt, and all about … his sex life. I knew everything about him … he had his friends, but he wasn't going to tell his innermost secrets and things to his friends. So, that is where I found it really difficult and so did Brenton.

For those who could not speak the unspoken there was always a doubt that the subject of death and dying could have been broached. For example Fulvia, despite wanting to bring up the topic of death and dying, felt that because they were always being positive they didn’t have the opportunity to bring it up which she regrets:

I sort of regret, I did try once, I said Jadye, “do you want to talk about it?” [dying]. She said, “talk about what?””, she didn’t want to talk about it … We were all trying to be positive and I wish, I could’ve talked …, it’s a hard topic.

Cheryl has a similar regret and she wonders if she could have pressed the issue more:

I don’t feel that we ever really explored … you’re going to die stuff … and I don’t know whether or not we should’ve …. It’s always been … in the back of my mind that maybe I’d let him down. I didn’t push that issue and maybe I should’ve done.

**Being There**

In order to stay connected it was important to be with the AYA whilst they were in hospital. This occurred in various ways and required some sacrifice on the part of the family members.

For Cathie the sacrifice for being there for Paul Vincent was exhausting as she sought to combine caring for Paul Vincent with her other roles of working and mothering:

[I] went through a really hard time with it all … trying to visit Paul in my lunch breaks, plus I was breast-feeding a baby and working, running up to the pump to breastfeed then race down to see Paul and then race after work to see Paul. I got down to 6½ stone I was really thin and really worn out … So … it was a very difficult ride for me in a selfish sort of way because I had a young baby and I spent my whole life at the hospital.
Tania remembers there was no choice in being there, it was just something you did to make it as easy as possible for everyone. She recalls that some things had to wait as everyone chipped in:

she had someone there all the time, there wasn’t any time when there was no one there for her … some things get put on the backburner … we all sort of chipped in to make it as easy as possible. It was just a part of life that we had to deal with … and we’d go to the hospital and help Susie … it was just something that we had to do … you don’t have a choice, you just deal with it, you have to.

This is similar to Lauren who spoke of her expanded roles that she took on so her Mum could care for Grant. In addition to these expanded roles, she sought to be with Grant as much as she could and be supportive by acting as a backup for her Mum:

in terms of caring for Grant I really thought that Mum had to do that, so I just took care of the other stuff. I was doing a lot. I started doing a lot of the home stuff as well. I started cooking and cleaning and shopping and doing all those things while Mum was at the hospital. I was also trying to study and work and be the vice president of CanTeen and also trying to be there with Grant as much as I could. When mum couldn’t be there … if she went to work for the day then I would be at the hospital, so I was the back up for her. It was kind of crazy. I think for Mum, I was sort of the support for her. I think as long as I helped it helped Mum.

The previous family members spoke of how they juggled their life and work in order to be with the AYA and provide the support they required. Not all family members found being with the AYA easy. For example Val, the whole time Anthony was in hospital, would make excuses to leave, only to go back again:

I would sit there for a couple of hours and I would come up with the most amazing excuses why I had to go out for a couple hours, but then when I got out of the hospital I had a smoke, I’d go to drive home, and I’d think no, I can’t do that and I’d go back, and that happened every day that he was in hospital.
This seeking to be there was not always easy because of various attitudes within the hospital system and the age of the AYA. Fulvia had to push to have someone to stay with Jadye because the system didn’t think she needed someone to stay with her overnight:

\[
\text{in an adult ward, [the nurses would say] “oh come on Jadye, what’s wrong with you, why does your mother have to stay here the night? … come on grow up, you don’t need your family” … They wouldn’t let anyone stay with Jadye overnight and we pushed and pushed that until someone stayed, it didn’t matter, we weren’t leaving her alone for one minute.}
\]

This is different for Arlene who didn’t push to stay with Mathew James overnight. She believed that was what the staff and Mathew James wanted because he needed to be independent and not have her caring for him all the time. She said she felt judged and never asked the question because regardless of the answer the outcome would be negative. It was only towards the end of the transplant that she found out that Mathew James had actually wanted her to stay overnight:

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\text{If there were adults being treated at the time the partners of the adults often stayed overnight, stayed 24 hours if they wanted to but I felt that the staff were quite young … I felt that they looked at it as an eighteen year old shouldn’t have his Mum pawing him all the time, fiddling with him all the time, so there were things I didn’t do that I wanted to, which upset him and I didn’t find out until near the end of the transplant time that he wanted me to stay overnight. I thought that he wanted me to go home and give him his independence and that that was what the staff wanted me to do. And yet at the same time I didn’t feel that they judged the adult patients, or the sons or daughters. But I just felt that they judged me. … I was never game enough to ask the question [about what the staff thought or expected of me] to find out if it was true, because if they said “yes it’s true,” then I would feel worse than I already did. If they said it was not true then I would feel an absolute idiot. So, if the question was never asked I never had to work it out, which is stupid, because it means that not asking made things more difficult for myself.}
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Helen believed she may have smothered Mick a little bit during his first admission, as she was there all the time, although he told her he felt safe when she was present:

> Although he was always glad to see me and I remember one day … sitting there, I came over about 10 o’clock, he was sound asleep … and I just remember sitting there, looking at him sleeping and thinking why, just over and over. The lady came in to get the menu … and it woke him up and I said, “oh sorry Mick, I didn’t mean to wake you,” and he said, “that’s all right, I feel safer when you sit next to me.”

**Being Involved with Care**

For the family members being there also meant that many of them were involved in the physical hands on care. This made the powerlessness and lack of control of the reality of hospitalisation and the inevitability of treatment a little easier to handle.

For some, being involved with care was because the hospital was very busy and the family member would help out as much as they could. For example, Deborah spoke about all the parents being involved with care because the nurses were too busy and, as a result, the parents would leave bottles and vomit bowls in the pan room with the name and time on a bit of paper.

> [Nurses] were really good. Busy, short staffed, run off their feet. Because he had a lot of fluids going through him, he was using a bottle, a lot, and vomiting a lot … all the parents there knew where the pan room was … and what we had to do when we took a bowl of vomit in there was leave it sitting … on the bench there with a note saying … whose it was and what time it was done, and we’d collect a fresh bottle and bowls for vomit, because the nurses … were that busy you’d buzz for a nurse and you’d be waiting for ages, so it was just easier to do it yourself. And all the parents there were doing it … they were really, really good.

Fulvia wanted to care for Jadye and with the nurses being busy it meant they did everything. She wondered who cared for the other people on the ward:

> Jadye’d be vomiting and I’d be running around going where’s the vomit bowls … We showered her, we made her bed, which I wanted to but if we
didn’t, I don’t what happens to the rest of the people on that ward. All we got was, “we’re busy, we’re busy, you’ll have to wait, you’ll have to wait.”

Arlene also wanted to be involved in Mathew James’ care and spoke to the staff about the things she could help with during his bone marrow transplant. Providing care for Mathew James allowed Arlene to have some control over what was happening to Mathew James:

I didn’t want control taken out of my hands … I let them know at the beginning that I was a nurse and that I’d always been involved in his care and that I would appreciate being allowed to do things for him. I couldn’t stand back and not do things for him. I wasn’t talking about doing anything complicated … wanting to do things like keep his fluid chart up to date or dial up his IV fluids, which I could write on the fluid chart, and I would let them know that I had done it so that they didn’t have to worry about coming in every time it beeped. I could do the routine catheter care, the CVC dressing and whatever if necessary. There were lots of little things I could do without taking over their work and getting in their way.

**Keeping a Watch**

This being there and being involved with care resulted in the family members becoming intimately involved in the AYA’s care. Many of the family members were familiar with the treatment regime and kept a watch to ensure that the AYA received the right treatment and were protected from any adverse outcomes.

The subtheme ‘keeping a watch’ involved the family members ensuring that the AYA received the most appropriate care. This is seen in Deborah’s story when two nurses were wanting to give Matthew Anthony his chemotherapy in a different time frame. The nurses did not believe her, but on Deborah’s insistence the doctor was called and Deborah’s correct time frame confirmed. From then on because she didn’t want anything to happen to Matthew Anthony, she kept a watch on his care:

[there were] 2 nurses coming and checking the chemo and hooking it all up … [they had] almost had pressed start … and I said, “that’s not right, he has it over 2 hours.” And they said “no, it’s 20 minutes” and I said, “No, he has it over 2 hours” and they were like well, we’re the nurses and you’re
not, I think we know, and they both agreed that he had it over 20 minutes and I just said “right, that’s it, you are not putting that stuff in him until I get a doctor to confirm it because … this is the way it’s been for the last couple of months, he has it over 2 hours.” Anyway they sort of … went off in a huff and came back and actually apologised to me because I was right, it was over 2 hours … and after that I watched everything and I know they’re tired. A lot of them were doing double shifts, they were understaffed, overworked, mistakes can happen, I understand that but I wasn’t going to let anything happen to Matthew.

Keeping a watch was tiring and frustrating for Fulvia. She felt angry because she was always fighting and watching to ensure mistakes didn’t happen:

when Jadye got sick I thought okay, I’m a nurse and I let it be known that I know the hospital system and I’m not going to let mistakes happen … and … I really thought I was on the ball and it’s really frustrating. You end up an angry person, you’re angry and you’re tired and frustrated and you’re fighting with them and you’re watching.

Lauren also spoke about fighting for things to happen but at times not being sure if she had made the right decision. She had also been given Power of Attorney for Grant’s health directive and despite the fact that she had looked after Grant all her life she still found it difficult having that responsibility:

I definitely fought for things to happen. Grant gave me his power of attorney for his health directive, so that if it ever came down to him being … unconscious or he needed surgery or something like that I would make that decision based on the guidelines that he had set out for me … I had his legal power of attorney … in some ways in terms of dealing with the doctors I was probably more responsible. They’d give me a call if there was a problem and it would be me asking the questions it would be me pushing for whatever [which] I thought was right [but] which may or may not have been right. It was hard, I do feel responsible but it had always been the way it was … he was my little brother and I looked after him my entire life.
Deborah, Fulvia and Lauren fought to ensure that their AYA received the best care and treatment possible from health care workers and the health care system. Helen and Geoff on the other hand kept a watch by making sure that Mick was protected from infection. Geoff saw this as protecting your own:

people ... go in and they [say] “oh I just want to give you a kiss,” and ... you say “oh, have you got the flu?” ... we made up extra signs ... and I’d just say “well look, have you washed your hands?” [and they would say] “No, what do you want [me] to wash [my] hands for” I said “well, read ... signs ... wash your hands, if you’ve been crook just don’t turn up.” The bottom line is, talk to him over the computer, talk to him over the phone. It’s sort of something that will never go away, that type of memory. It’s a protection thing, you’ve got to protect your own, haven’t you? ... it’s really hard, and I don’t think a lot of people are aware of this that much ... it’s the kiss of death sometimes. It’s hard for yourself too, a few times there Mick would always want to hug you or give you a kiss or whatever, in the back of your mind you’re thinking, “oh ... am I coming down with a cold or something.”

**REFLECTION ON STAYING CONNECTED AND SUPPORTIVE**

The first four themes of the Exploration stage of the cancer journey for AYAs and their families demonstrate how difficult it was for the family members to alleviate the pain and suffering that is associated with cancer and its treatment. The family members were required to assimilate the information associated with treatment whilst at the same time not being sure of the information or what questions to ask. All found the experience within the hospital space of the cancer landscape difficult. Witnessing the effects of treatment was hard, which was compounded by the practical difficulties associated with treatment. As a result of this the family members were engaged in living the chaos narrative in which they were powerless, helpless and had little control of what was occurring within the cancer landscape. Compounding these three themes was the realisation that there was no real place or space in the system for young people with cancer. From the stories in this study, the family members sought to gain some control
over the chaos narrative by attempting to stay connected and supportive of the family member during treatment. The family members stayed connected and supportive both physically and emotionally in the following ways, strengthening existing relationships, sharing the unspoken, being there, being involved with care and keeping a watch.

As mentioned previously while exploring the cancer landscape, the AYAs on the cancer journey have left their previous path with the relevant developmental milestones. Rolland’s (1987a) family systems model speaks of a centrifugal pull on the family system with an emphasis on internal family life. This centrifugal pull has repercussions for the AYA and their family as each families’ extra familial autonomy and individuation are at risk, compromising this transitional stage of individual and family development (Rolland, 1984, 1987a, 1987b; Veach, et al., 2002). This is seen in the AYAs and family members in this study when the AYAs explored the cancer landscape they become more dependent on those around them due to the isolation and effects of the cancer treatment.

The stories speak of the development of strong bonds and strengthening existing relationships. Relationships were strengthened for various reasons such as not being able to complete normal developmental milestones and needing the intense care of the family member, as with Arlene. The bonds that developed for Deborah were what she describes as soul mates as evidenced in Deborah’s story. Both these stories demonstrate a centrifugal pull as the mother-adolescent bond intensifies. This is identified in the literature in which seven young adult cancer survivors spoke with great affection about their mothers and appreciated the caring and sacrifices and many speaking of an intense bond which developed between the mother and adolescent because of the experience (Neville, 2005).

This centrifugal pull and the strengthening of existing relationships made it possible for the AYAs and the family members to engage in dialogue in an open and honest way. This resulted in discussions and reflections on topics that may previously have been taboo for the family members and the AYA. This extended to opening up communication and providing information to the AYA about what to expect on the cancer journey. Speaking of taboo topics was difficult for some family members, as told by Jenny, as information was shared which would not normally be discussed with an AYA and their parent. Once again, reflecting the missed opportunity to achieve normal developmental milestones. Sharing the unspoken resulted in opening discussion about
death and dying. Those who missed the opportunities to talk about dying felt a sense of disappointment.

Therefore, strengthening of the bonds provided a safe haven in which to talk openly and honestly about issues associated with the cancer journey. Of particular importance was the opportunity to talk about the possibility of dying and uncertainty about the future. This is highlighted in the literature in which AYAs exploring the cancer landscape have various concerns and uncertainties about the future that they would like the opportunity to talk about (Carlsson, et al., 2008; Decker, et al., 2007; Decker, et al., 2004; Neville, 2005; Palmer, et al., 2007; Patterson, et al., 2008a; Woodgate, 2008). In one study AYAs identified unmet needs, which included help with dealing with feelings of distress, sadness, fear, frustration anxiety about possible side effects and uncertainty about the future (Patterson, et al., 2008a). From the stories in this study the unmet needs are discussed mainly with a family member and not a health professional. The missed opportunity to talk about the AYA’s mortality is confirmed in a Swedish quantitative study by Kreicbergs Valdimarsdottir, Onelov Henter, Steineck, (2004). In this study the researchers contacted all parents in Sweden whose child had died of a malignant disease between 1992 and 1997 out of a total of 561, 449 responded. The study involved a questionnaire in which some of the questions related to talking to their child about death. The study found that of those parents who talked to their child about death, none of them regretted this decision. In contrast, nearly a third of parents who had not talked to the child about death regretted their decision. This tends to confirm Fulvia and Cheryl’s sense that maybe they should have spoken to Jadye and Paul Malcolm about dying.

The family members in this study worked hard to be with the AYA as much as possible when they were exploring the hospital landscape. The desire to support and protect the AYA did not come without some cost for the family member. Being with the AYA required family members to take a detour on the life path they had been travelling and explore with the AYA the hospital landscape. Family members spoke of the sacrifices they made to support the AYA, while at the same time trying to fulfill other commitments and roles in their life resulting in extraordinary demands on them. Family members believed there was no choice and life was just put on hold as they took on additional roles to support the AYAs. Wanting to be supportive and connective by being there was not easy and some found the experience emotionally exhausting.
All the family members in the study wished to be with the AYA, although this was not always facilitated by the hospital system depending on where they were cared for, and the attitudes of the hospital staff. Those family members whose AYA was cared for in the adult system were confronted with some barriers and dilemmas of how much time they could be there for the AYA. Fulvia believed the hospital staff thought it was not appropriate for the family member being with the AYA and she had to insist that they be there for them; whilst for Arlene it was inconsistent messages from staff. Added to this was the dilemma of how much time was appropriate to give to the AYA with the belief that they required autonomy and independence. This dilemma of how much autonomy and independence the AYA required resulted in family members at times not being present when the AYA would have appreciated the family member being there.

Staying connected and supportive was not just associated with being with the AYA as much as possible, it also extended to providing nurturing and physical care. This extended to providing treatment at home, helping the nurses out because they were so busy and short staffed, letting the nurses know how they could assist with care to doing everything for the AYA. This providing of physical care was something that the family members wished to be involved with and was made easier if the health care professionals facilitated this provision of care. This involvement in care gave the family members a sense of having some control over the cancer journey and not being immersed in the chaos narrative.

Being involved with care and being there resulted in the family member having knowledge of the treatment regime and an in-depth understanding of what the AYA was experiencing. This acquired knowledge resulted in the family members ensuring the AYA received the best possible care and the correct treatment. This also further reinforced the family members having a sense of control over the cancer landscape and where the journey would take them. This was achieved by keeping a watch on the treatment given, being aware of other medical interventions that may be required, advocating for the AYA when there were problems, and acting to protect and prevent the development of problems.

This staying connected and supportive is an important predictor of psychological health for an AYA with cancer, with AYAs with high levels of uncertainty and low levels of social support having the greatest psychological distress (Neville, 1998). Woodgate’s (2006a) study found support was provided to adolescents with cancer through a
person’s psych-emotional presence and by being there to comfort and reassure the adolescent throughout the cancer journey. According to Ritchie (2001) this psych-emotional support such as handholding and being there decreased treatment related pain. Lynam’s (1995) findings reveal that families play an integral role in offering support to young adults with cancer. This support involved establishing caring partnerships, acknowledging the possibility of death, putting the illness in its place, looking towards the future and recognising the role of others in supporting the young adult. Of most importance in this study was the family’s ability to be there for the young person who has cancer.

**Theme: Recalling What Helped**

The previous four themes tell a story of the AYA and family members entering into a journey over which they have little or no control and living the chaos narrative. Although the stories in the theme staying connected and supportive allowed the family members to feel they were doing the best they could and provided some form of control over their feelings of helplessness and hopelessness. This was through their ability to support and care for the AYA on their cancer journey. This support and care was accompanied with sacrifices and life being put on hold. Many of the stories mentioned how hard it was to provide the care that was required. Given all the chaos that was occurring around the family members in this study, you would assume that the family members would be cognisant with the things that made exploring the cancer landscape easier. It is interesting that only half of the stories spoke of things that made this journey easier. The things that helped the most were the practical, physical support and social support offered to the AYA and their family. Others things which helped were the family members being able to observe special relationships that were developed with the AYA and a health care professional, which made the treatment and hospital experience more bearable.

**Providing Support**

For Denise this practical support offered was helping her and keeping her informed of entitlements:
and on my side of it the social workers there were fantastic in keeping me in the know of what I could have, how they could help me and everything that was available to me … So that side of it was really, really good.

With Denise the Social Workers kept her informed of all her entitlements, while for Alan it was the simple things like having a staff car parking pass which made the experience easier and less expensive:

we were told by the social worker and thankfully she was someone who would listen, and was really good at her job … She said, “once she’s been in here for 21 consecutive days we can give you a car parking pass to get in at the same rate as staff,” and … I said, “that’s ridiculous … it’s highly unlikely that they’re going to be in for 21 consecutive days,” [she then said] “okay, leave it with me” … it was $2 a week.

Denise and Alan both provide accounts of how the Social Workers in the hospital system provided the support that made the hospital stay so much easier. This is different to Kerry who, despite having a social worker, there appeared to be gaps in Alinta’s care plan and they had nowhere to stay when Alinta returned to Brisbane for radiation therapy:

I know people can’t work 24 hours too, but there’s a social worker there but she was just about getting married and she was human and she wasn’t real good … when we were going back up for radiation … we didn’t have anywhere to stay, we weren’t allowed to use McDonald House … We weren’t allowed to use the Leukaemia thing … because it wasn’t leukaemia. We were outpatients.

For Pam no Social Worker provided support and it was the Queensland Cancer Fund that helped:

through the Queensland Cancer Fund … they were helping me … They were very good to us, but see the hospital system … nobody suggested a social worker.

Similar to Pam it was the Cancer Council who provided respite for Fulvia and Jadye with a week in Cairns. This respite was appreciated with Jadye being her old self again:
the Cancer Council gave us a week, Shauna, Jadie and I went to Cairns for a week, take a break from Cancer … and that was probably the best thing that happened to us … Jadie was just back to her normal self … for some miraculous reason that week she was not ill, she forgot … and the cancer was gone at that stage. It came back not long after but it was just really good timing.

This social and practical support was not exclusive to the health system or organisations that provided support for people living with cancer. For Geoff the support was through the Police service and he was able to temporarily relocate his job to Newcastle. This meant his work was not disrupted when Mick was being treated in Newcastle:

it was a good choice going there, we’d spent a lot of time in Newcastle, we were familiar with the area, we had friends down there … the police service there said “look, you can come down here and you can work here anytime, to save any sort of drama with work, rather than using up all your leave and when you really need it you won’t have any.”

Geoff and Helen’s work also provided counselling for Mick when he was in hospital as Helen had found it difficult to access counselling services within the health system:

[Mick] wasn’t coping particularly well, and that’s when I tried to get him some sort of counselling, some sort of mental help but I ran into the problem … So what I did I rang up EAP, which is the Employees Assistance Program, which the police and the teachers can go to for counselling … But then they said “there is this young fellow in Newcastle, try him,” and we rang him and he was only too happy to come to the hospital … and he was just so good, but that was outside the health system. I had to go through our work.

Observing Special Relationships

As mentioned in providing social support, it was the practical things that made the cancer journey easier. This is also noted in the special relationships that the family members observed the AYA forming with members of the health care team. These special relationships made a difference to the AYA’s care and treatment. The majority
of these relationships were with staff who took the time to get to know the AYA and treated them more as a person and less as a patient.

Denise observed the special relationship that Brenton James developed with a nurse. This nurse stood out, she was close to Brenton’s age and treated him appropriate to his age. There was a lot of friendly banter between the two of them. Her relationship with him was more than just a job and because of this, he felt safe with her:

she was young enough to be close to his age … probably in her mid twenties now … if he grumped, she grumped back. She’d say, “righto bossy boots, come on” … and they’d [go] back and forth to each other and he would grin all over his face … she related to him being a teenager and she treated him as a teenager but as an equal as well and not someone who fuss ed over him all the time or someone … that [saw it as] their job and that was it. She really, really cared about him and he knew that … she treated him not with pity sort of thing … she stood out, she stood out. They were all lovely and he appreciated them all but this particular nurse he just took a real liking to her and he felt safe.

This is similar to Mick when Helen talks about the relationship he developed with his counsellor who made the biggest improvement in Mick’s mental state. He took the time to listen and give Mick the space to talk:

this fellow would just come and sit with Mick for hours in the room and just talk and talk and talk to him, about anything and everything that Mick wanted to talk [about], and that made the biggest improvement in that kid that you could imagine.

This is different to Shane where it was not just one special relationship that made the AYA feel listened to, cared for and special. For Shane it was the whole treating team gave the impression that Grant was special:

they were sort of like family themselves, like they cared so much about him, it was almost like Grant was special, we kept on getting this feeling that he was special. And he couldn't have been any more special than anybody else,
at the time, but they gave us that feeling ... All the nursing staff, all the doctors everybody seemed to take him under their wing.

**RELECTION ON RECALLING WHAT HELPED**

The account of the cancer journey for the AYA and their family is one that is hard and difficult. Despite this, family members spoke of things that made the journey easier for them. These included the practical and social support that was offered during that time, and special relationships, which made the journey easier.

From the previous stories the social support offered to the families and AYAs is a hit or miss affair, with social work services being offered to some and others finding these services inadequate. Those family members who were provided with adequate support from Social Workers found it made a big difference in how they managed to explore the cancer landscape.

Others found cancer care organisations outside the health system provided support, with some not being offered the services of a social worker. For Geoff and Helen it was the support offered through work with flexible working arrangements and the employee assistance program. This haphazard delivery of psychosocial support is recognised in the Guidelines for Hospital-based Child and Adolescent Care noting that the specific health needs of young people often go unrecognised and are a challenge for health care workers (Association for the Welfare of Child Health, 1998). These unmet psychosocial needs could be related to the fact that the services available in the adult hospital are designed to meet the needs of patients over 60 years old who are the majority of the patients. Palmer et al (2007) indicated that some young people may have no contact with a Social Worker during their entire treatment. When considering psychosocial care for AYAs and their families the OnTrac Victorian Adolescent Young Adult Cancer Service, Practice Framework suggests a preventative approach in which an AYA is offered the support of a Social Worker at the time of diagnosis. Although this is for the individual patient, this support may be beneficial if it includes the whole family unit.

Social support that helped makes the cancer journey less demanding includes the special relationships that the AYA developed with others that made the journey less daunting. These special relationships were mainly with health care professionals who took the
time to get to know the AYA and treat them more as a person and not as a patient. These were relationships in which the AYA felt treated as a normal AYA and not as a cancer patient. The relationship was not exclusive to a one on one relationship as it could also include the whole treating team. The development of special relationships helped the AYA and the family members explore the cancer landscape. Although similar to the previous subtheme on the provision of social support, the development of these relationships appeared to be more related to good luck than good management. This may be a reflection on the lack of education and understanding of the age appropriate behaviours of AYAs and how to care for these patients. Palmer and Thomas (2008) provide quick tips for working with AYAs which includes being aware of the young person’s developmental stage and how this will effect exploring the cancer landscape. Whilst another tip includes having a holistic approach to the young person which would enable the health care worker to better understand what will interest and motivate the AYA. A holistic approach would no doubt include the family system.

**Theme: Living the Quest**

The experience of the cancer journey, as told so far, would leave one believing that the AYAs in this study would be overwhelmed with the experience and find it difficult to get on with life. This is not the case, with over 75% of the stories speaking of how the AYAs sought to approach their cancer with courage and dignity. The attitude with which the AYA approached and negotiated the cancer landscape spoke of resilience and hope. This attitude made it easier for family members to deal with the hopelessness, helplessness and lack of control associated with the cancer journey. Many of the family members spoke of the AYAs’ courage and ability to continue with life as best they could. This is demonstrated in the following theme living the quest which involved the AYA taking the cancer journey in their stride and seeking to be normal.

*Taking It in Their Stride*

Deborah noted that, despite the bad days, Matthew Anthony was the family’s strength. He managed this by being able to inspire her to focus on the family more, and due to his sense of humour she found it easy to be happy around him, even when he was really sick:
I actually, you know I had a lot of bad days but Matthew … he was our strength. You couldn’t be a misery guts around him … he brightened the room up even when he was really, really sick … I started to really focus on the family more … and Matthew sort of inspired … and encouraged that. … he had a real sense of humour and it was very hard to be miserable around him.

Heather and Trish tell a similar story when talking about Paul Vincent’s bravery, because he never complained despite what he was going through and how sick he was:

and he was really crook and he never let on that he felt crook even though you could tell … He was the bravest, he was amazing … I remember reflecting on it after he died and thinking all that stuff he went through he never complained once, never … it was as if there was nothing wrong even when he felt the sickest of sick.

Irene reflected that for her ‘taking it in his stride’ was the amazing way that Thomas handled his amputation, showing her his amputated leg after the operation then running around the hospital on crutches. Similar to Paul Vincent he never complained and coped very well:

yes … he was just amazing, absolutely amazing … within an hour of him coming out of the anaesthetic he was on the phone to me. He said, “I’ve been on to picture, look and you can see me with my one leg gone.” I couldn’t believe it … once he was on crutches … there was another boy in there [who] had the same thing … he and Thomas used to run around the hospital like lunatics, on these crutches. They used to have the nurses in stitches so Thomas coped with it very, very well … I couldn’t believe how strong he was … He just never complained, never … I just never, ever heard him complain.

Taking it in their stride was also reflected in the way that the AYAs decided to get on with life despite the effects of the cancer treatment. Denise spoke of how Brenton James minimised the loss of his eye by playing a round of golf with his friends:
then we came home and he, immediately the next day, being a teenager that nothing worries them, he said to me, “Mum it’s only an eye, I’ve got another one I can get on with my life,” and he went out the very next day, which was 4 days after the operation and played a round of golf with his mates.

Taking it in their stride and getting on with life did not just extend to the AYA attempting to live with the after effects of the cancer treatment. It also extended to the AYAs looking towards the future. This is seen with Brenton Duncan who spoke with optimism about his future after his leg amputation. He believed life would be good:

so, then he had his leg amputated, and after that he came home, he said to me: “Mum, I’m free of cancer now, I’m going to get married one day, I’m going to be the best one legged golfer”, because he loves golf, and he said: “I'm going to, it's going to be really good, life's going to be good”. And I said: “Yes love, we are going to really move on now”.

Similar to Brenton, Matthew Anthony also had goals for the future, a house, job, marriage and adopted children:

He had goals, he was dead set, he was going to be an electrician. He was gonna buy a house and do this and do that and then he was going to get married and him and his wife were going to adopt children because he was told that he would never be able to have children.

Seeking To Be Normal

When the AYA had some reprieve from the treatment regime, rather than focus on the cancer journey and the cancer landscape, most wanted to engage in normal AYA behaviours. For some this normal behaviour was as simple as being able to attend school.

This was noted by Cameron who knew Kristie wanted to be a normal teenager and attend school even if she was sick:

when she was well enough, she wanted to be (at school) she was a very educated young lady so she wanted to be there any time that she could get
free … even when she was sometimes sick she wanted to go to school just to be normal. She was a teenager she didn’t want to be in hospital.

Similar to Kristie, Helen said Mick wanted things to be as normal as possible. Going back to work was his way of taking charge of his life and this created a dilemma for Helen who thought he could have looked after himself better, but knew he wanted to lead a normal life so she tried hard not to be overprotective:

*Sometimes when I think of when he was in remission, maybe he could’ve looked after himself a little better, not that he did anything particularly wrong, but he still didn’t let it stop him … he didn’t have to go back to work. His boss said on his apprenticeship that he could take off as long as he wanted but he wanted to get back to work … and feel like that he was still in charge of his life and he just wanted things to be normal and that was his way of making it as normal as possible. [I] just tried not to be too over protective of him because he wanted to do things, get back to normal.*

This search to be normal also involved the AYA requesting flexibility in their treatment. For example, in order to go camping Ben requested his surgery be delayed for a week. Sue like Helen was worried but it was worth it because he had a great time:

*Prof said “we’ve got to take his gland thing,” and Ben said, “can you put it off a week,” he said, “I’ve got something to do” … He said “I’m going with Venturers, we’re going up the mountains” … I worried myself sick when he went on Dragon Skin because that’s 4 days through the bush … but he came out the end fine … and then I saw some photos about it, the places that he went and the tiny spaces he crawled, and I thought I’m glad I didn’t know what you were doing because I would’ve had heart failure I think … he had a ball, he loved it.*

For others, this seeking to be normal was the creative way they explained the effects of treatment. Pam spoke of Tamina trying to normalise her scar by telling others it was a result of a crocodile attack:

*she went all through the teen life with this big scar down her leg and she was amazing. People would say to her what happened to you, and she’d say,
“oh I got attacked by a crocodile” but if she told them she had a tumour on her leg, they didn’t look at it.

**Reflection on Living the Quest**

The stories in this theme speak of the AYAs seeking as much as possible to minimise the effects of cancer by engaging in behaviours which made it possible for them to minimise the impact the cancer was having on their lives. This minimisation of what is encountered in the cancer landscape is symbolic of what Frank (1997) refers to as Quest narrative. The quest narrative is an archetypal hero’s journey in which a hero crosses the threshold into another landscape where he must endure the supreme ordeal (Vogler, n/a). The AYAs in this study began the Quest when they departed from their familiar landscape and began exploring the unfamiliar fearful cancer landscape. The family members’ experiences speak of how the AYAs on this quest endure the supreme ordeal with courage and dignity.

There were numerous references by the family members of the AYA taking the cancer journey in their stride, despite being really sick with the treatment. This attitude made it easier for the family member to endure the cancer journey. The AYAs provided strength and inspiration as family members witnessed the AYAs humour, strength, bravery and ability to never complain.

This ability to deal with the cancer journey could be explained as examples of guarded communication, which Neville (2005) witnessed between parents and adolescents with cancer. The adolescents protected their parents from their own concerns, as they believed their parents were already overburdened with fear and concern for the AYA. Although this does not appear to be the case for many of the family members in this study, as noted in the subtheme sharing the unspoken, where parents and adolescents discuss intimate aspects of their life including death and dying. This was confirmed by Grinyer’s (2002a; 2008) study where the parents describe talking to their son or daughter about issues which would previously not have been discussed.

For others this quest and taking it in their stride involved taking on board the losses that occurred as a result of the cancer journey; accommodating the losses associated with their body image and sense of self. These losses ranged from the loss of hair through to
the loss of organs and limbs and many of the stories speak of minimising and normalising these losses. This getting on with life involved the AYA, despite suffering from the treatment and incorporating the losses into their life, still having an optimistic view of the future.

Throughout the ordeal the AYAs had a belief that life would return to normal and they would eventually achieve the normal milestones expected for an AYA. This assumption that life will return to normal is a theme that has been spoken about in this study’s literature review and follows next (Decker, et al., 2007; 2004; Evan & Zeltzer, 2006; Miedema, et al., 2007; Patterson, et al., 2008a).

Following on from the theme taking it in their stride, the quest involved the AYAs seeking to maintain as normal a life as possible, some of these behaviours included going back to school or work, staying in touch with friends, engaging in normal teenage behaviour, delaying treatment in order to engage in AYA activities and normalising the scars they had received in surgery.

Despite the fact that the AYAs were a part of the cancer landscape and enduring the ordeal which is the cancer journey, the AYAs managed this ordeal and lived the quest by, whenever possible, taking the ordeal in their stride and stepping back onto their normal path. This attempt to be normal and taking it in their stride is a common theme for AYAs with cancer (Decker, et al., 2007; 2004; Evan & Zeltzer, 2006; Miedema, et al., 2007; Patterson, et al., 2008a). Woodgate’s (2000) review identified this attempt to be normal as children and adolescents create a new normality for themselves which incorporated the cancer experience. This is seen in this study with the AYAs minimising the cancer symptoms, almost to the point of denial.

**Anticipation**

**THEME: SENSING A REPRIEVE**

The quest narrative is a narrative of the hero once they have endured the ordeal returning to the familiar path that they had been on before, albeit changed from the experience. For the cancer journey this occurs if the person is told they are in remission. Throughout the Exploration stage of this study, there was always the sense that at the
end of the Exploration stage the AYA would be cured and the horrible experience had all been worth it. This relief was experienced by 13 family members in this study with 25 references; they believed that the AYA was in remission and they could get on with their life. For the family members this was associated with the results of the tests and being told the AYA was probably cured.

For Denise, the frightening experience was over and they could get on with their life when the specialist said Brenton James was unlikely to get cancer:

> we had another appointment, and his specialist said that as far as they could tell they’d got everything, there would be no more worries and he had as much chance as any other child, or any other adult, of getting cancer. So this was a really big relief to us … thought well … we’ve had our big fright in life, he’s coping well and we can just get on with our life.
Lauren tells a similar story. Although they were told Grant wasn’t cured they decided to get on with life:

they told us that he wasn't cured but that the tumour had gone and that if he didn't have any re-occurrences in five years he would be cured. And they said they believed he will be cured, that there was a great chance and they were very happy. We were having checkups sort of over the holidays, but … we just let it go and lived our life.

Fulvia and Jadye celebrated the reprieve with a party believing everything was better:

And within 10 days the tumour was nearly gone and the pain had gone and everything was fine and she had her full doses of chemo and the tumour went away and they said if it doesn’t come back within 2 years she’s fine … the first time the cancer went away we all had a big party and Jadye was better.

REFLECTIONS ON SENSING A REPRIEVE

The treatment stage of this study was all associated with the possibility that the AYA would be cured and at the end of treatment, it would all be worth it with the AYA being cured of cancer. For those who felt they had a reprieve there was a sense of relief and a feeling that they could now just get on with their life.

This sensing a reprieve is what Frank (1997) would describe as the restitution narrative in which the person who has been sick is well again and can return to their previous path. Frank (1997) says this is the most common narrative. The quest narrative requires that the hero share what they have learned through the ordeal with the rest of the world. Whilst the AYAs and the family members were living the quest and chaos narrative throughout most of the Exploration stage of the cancer journey, when there was a sense of reprieve they just wanted to leave the cancer journey behind them and continue along their previous path. The family members just wanted to leave the narratives in the unfamiliar landscape and return to the familiar landscape with the story not being told. This could be explained by the symptoms of post traumatic stress which some families experience after an AYA and their family have explored the cancer landscape (Evan &
Zeltzer, 2006; Kazak, et al., 2004; Kazak, et al., 2005; Neville, 2005). This results in avoidant behaviour, a seeking to dissociate from the cancer journey. This is further confirmed in Grinyer’s (2002a) study in which the majority of the parents who told the story of the AYA were parents whose son or daughter had died, (20 out of 27) suggesting that survivors wish to leave the story behind, but if the son or daughter had died it was important for their story be told.

**DISCUSSION OF THE CANCER JOURNEY: DEPARTURE, EXPLORATION AND ANTICIPATION TURNING POINTS**

The Exploration stage of the narrative for this study saw the family members and the AYA enter an unfamiliar and fearful landscape as they become ‘citizens of the sick.’ In order to explore this unfamiliar and fearful cancer landscape, they are provided with a map by health care professionals who will be assisting them on the journey. The family members and the AYA must interpret this map without any knowledge and understanding of the cancer landscape and the journey they are about to undertake. For some of the family members, interpreting this map was made difficult because of this lack of understanding of the map, or not being given enough information about how to interpret the map in order to make informed decisions. Other aspects which made it difficult in interpreting the map was related to who, where and when the information is given which was determined by the health care professional(s).

To cross the threshold and become citizens in the kingdom of the sick involves entering the places and spaces that are part of the cancer landscape. The place and space of the cancer landscape is connected to the paediatric or adult hospital system. The majority of AYAs in the adult cancer landscape found the landscape was not therapeutic and aesthetically not pleasant. Exploring the cancer hospital landscape required the AYA and family members to leave their normal routines. This had social repercussions for the AYA and the family members as they could no longer properly engage in previous roles, and were lonely and isolated from those who supported them.

The AYAs and the family members were dependent upon health care professionals to explore the hospital cancer landscape. These health care professionals, at times, did not demonstrate an understanding that the AYA and the family members required empathic communication, given the foreign cancer landscape they were exploring and the associated suffering which was a part of this landscape. Dependence on health care
professionals meant that the AYA and the family members could only explore the hospital cancer landscape, when the health care professionals or the hospital cancer landscape could accommodate this exploration. This resulted in family members and AYAs having to wait at times to continue the cancer journey. For some this waiting was associated with an unexpected happening on the cancer journey, and the family members and the AYA having to explore terrain in the cancer landscape for which they were not prepared. The hospital cancer landscape is a space where illness and death are a possibility. This is most evident within the adult hospital cancer landscape where the majority of the patients are over 60. This resulted in the AYAs and the family members being confronted with illness, suffering and death, which for most was their first experience of mortality.

The hospital cancer landscape was mainly set up for either children or older adults. For some, exploration of the cancer landscape involved entering a landscape that was hard for others to enter, due to time and distance, and this resulted in an inability for peers to visit and limited opportunities for the AYA to engage in normal behaviours. Consequently AYAs experienced a sense of isolation. Added to this, the adult or paediatric hospital cancer landscape resulted in the AYA feeling displaced as they were surrounded either by old people or younger children in a landscape that appeared not to understand their unique needs. This isolation and not fitting in resulted in the AYAs not having the opportunity to talk to other AYAs who were also exploring the cancer landscape. Finally, because of the AYAs’ position within the cancer landscape, each system of care had limited understanding of the special requirement of AYAs.

Part of the cancer journey is the inevitability of the treatment that occurred in this landscape, which resulted in horrible physical effects that were difficult for the family members to witness. Some of these effects involved disfigurement and scarring from the operations that occurred in the cancer landscape. The cancer landscape is full of the unexpected at every turn with some of the AYAs not being prepared for the pain associated with the various procedures, whilst others had to endure more operations and procedures as a result of the side effects. For others there was the inevitability of treatment and the pain associated with the everyday experience of accessing a vein, which some health care professionals found difficult to accomplish.

The lack of a clear map of the cancer landscape and what to expect on the journey resulted in some family members not knowing where to go or what to do if there was an
unexpected turn in the journey. The experience of trying to explore the cancer landscape
was at times overwhelming, as the family members were not prepared for what might
occur, although they still worked hard to remain positive which at times was difficult.
This experience was described by one family member as like a roller coaster ride. All
these experiences within the cancer landscape resulted in family members feeling
powerless and helpless with little control over the cancer journey.

Despite the powerlessness, helplessness and lack of control, family members sought to
remain connected and supportive of the AYA as they explored the cancer landscape.
This was achieved by strengthening the relationships that existed between the AYA and
family members. These strengthened relationships provided the place for the AYA to
talk of intimate details of their life, in particular, dying. Some family members felt
disappointed that the opportunity to speak the unspoken never occurred and regretted
that the opportunity to open up a dialogue about dying never occurred.

To stay connected and supportive required sacrifices for the family members as they put
their life on hold in order to assist the AYA during the cancer journey. This was
achieved by attempting to stay with the AYA within the cancer hospital landscape. At
times this was made difficult because some of the health professionals, within the
hospital landscape found it difficult to understand why the AYAs required this form of
support. Some of the family members found it difficult to ask because there was a sense
that they were being judged. Added to wanting to stay with the AYA in the cancer
hospital landscape, it was also important that the family members were enabled to assist
the AYA with the physical care associated with the cancer journey. This was done by
helping out the nurses and providing as much care as possible. Due to their involvement
with care and time spent with the AYA the family members were cognisant of the
AYAs treatment within the cancer landscape, which resulted in them keeping a watch to
ensure that mistakes did not occur.

In order to make the cancer journey easier for the family members and the AYA, the
family members found the provision of practical support most helpful, such as
accommodation and concessional parking. The family members noted that the journey
was also made easier by the special relationships that the AYAs developed with some
health care professionals. These health care professionals seemed to understand the
needs of an AYA and treated them as a person and not a patient.
Whilst exploring the cancer landscape the AYA sought to do this with courage and dignity. Despite the ordeal they were going through they appeared to take it all in their stride. This extended to the AYA seeking to return to the previous path and engage in normal AYA behaviours whenever the opportunity arose. The expectation of the Exploration stage of the cancer journey was that eventually they would be able to return to their former path. For those who believed there was a reprieve, all wanted to leave the cancer landscape behind and continue with their previous journey.

The analysis and interpretation of the stories in this study has demonstrated that the majority of the family members stories had more similarities than differences during their, and the AYAs’ journey through the cancer landscape. Once the AYAs and family members had crossed the threshold into the cancer landscape with the cancer diagnosis, they entered a different and foreign landscape. The cancer landscape describes a space and place of isolation and lack of understanding of AYAs and their family. Communication was an issue, with the stories speaking of lack of understanding of the information and confusion about who should be told and when. There was also misunderstanding of how much support a family member should provide to the AYA, with many of the family members having to ‘fight’ to stay involved with care. Added to this was the negative hospital landscape in which the AYA and the family members found it difficult to explore and understand. Within this landscape the family members watched the inevitability of treatment, which for many was described as ‘horrible.’ All this suggests the importance of understanding this landscape and its impact on the AYA and the family.

Gesler (1992) advocates geographical inquiries which links landscape to health. The landscape is not only the space in which the person is treated but also it encompasses the physical and psychological environment. Added to this are the structural constraints that influence how an individual created meaning from an experience (Williams, 1998). These structural constraints influence the agency a person has over the landscape and are often related to individual needs or circumstances (Williams, 1998).

The landscape associated with the cancer journey is constructed by the symbolic meaning given to the journey. This symbolic meaning for the cancer landscape is the cultural values, social behaviour and individual actions associated with particular localities over time (Gesler, 1992). Part of this symbolic meaning is the sense of place or “the identity, significance, meaning, intention, and felt value that are given to places
by individuals” (Williams, 1998, p. 1197). This sense of place cannot be detached from the cancer landscape (Poland, Lehoux, Holmes, & Andrews, 2005). This is evident in this study in which the sense of place is the symbolic meaning created in the cultural and social milieu of the adult or paediatric hospital systems.

The sense of place from the hospital experience within the cancer landscape is associated with the aesthetics of the environment, the culture of the environment and the symbolic meanings of the hospital system, which includes the structuring of the experience and the therapy applied to healing the illness (Kleinman, 1973). The stories in this study, particularly in relation to the reality of the hospital experience, all suggest a non-therapeutic place which is not conducive to healing. Further to this sense of place is the typology of authentic and unauthentic landscapes. Gesler, defines unauthentic landscapes as “spatial separateness and isolation” (1992, p. 738). From this study the reality of hospitalisation is seen as an unauthentic environment as the family members and AYAs are isolated and separated from their familiar place. Added to this is the difficulty some of the family members experienced in wanting to stay connected and supportive in order to create a more therapeutic landscape. This is further augmented by the powerlessness and lack of control that accompanied the family members and the AYAs in the cancer landscape.

Poland et al (2005) argues that a clearer articulation of how place matters in health and social care has the potential for greater reflection on policies which influence place. Hebertson and Hancock (2005) maintain that worldwide there is no consensus as where and who should provide care to AYAs with cancer. The UK has the most coordinated approach to place with the establishment, since 1990, of designated AYA cancer units in various Trusts (Palmer & Thomas, 2008). In America the majority of AYAs are treated in paediatric settings whilst in Australia the majority of AYAs are treated in adult centres (Herbertson & Hancock, 2005). Despite the UK’s coordinated approach to AYAs with cancer Whiteson (2005, p. 9) states “[W]e cannot in all honesty say cancer services, anywhere, are offering the very best to young people with cancer.” She further states that “cancer services are delivered by an out-of-date infrastructure that by and large, fails teenagers and young adults” (p. 3). She considers care for young people with cancer should be seen as a right and not a privilege.

In Australia a Senate Inquiry in 2005 identified these difficulties and advocated an improved model of care to address this (Community Affairs Reference Committee,
2005). As a result, CanTeen and Cancer Australia have developed, in consultation with major stakeholders, a National Service Delivery Framework for Adolescents and young Adults with Cancer (CanTeen and Cancer Australia, 2009). In addition, the Clinical Oncology Society of Australia 2008 AYA cancer workshop recommended the development of national guidelines for the implementation of cancer services, and national coordination of functions to support AYA cancer services, such as research, professional development and evaluation, and the development of key performance indicators for AYA cancer services (Herron, 2008).

As part of improving the care for AYAs with cancer, Whelan (2003) advocated the establishment of Teenage Cancer units (TCUs) as an environment where appropriate specialist AYA cancer care can be delivered. These TCUs would meet the needs of teenagers with cancer by providing: expert nursing and medical cancer site specific treatment, appropriate information to AYAs and their families, an adolescent user-friendly environment, educational and social support, the ability to address the psychosocial needs of AYAs and their families, and acknowledgement and support through developmental transitional stages. This is further reinforced by Geehan (2003) who, as a 17 year old treated for osteosarcoma in a TCU, described the following benefits: the specialist nurses who were their emotional rocks and friends, reciprocal inspiration and support from other AYAs, the engagement of parents with care, and an activities coordinator which helped maintain a sense of normalcy and access to appropriate education and psychological support. Geehan (2003) failed to find any real drawbacks with the exception of close friends on the ward dying of cancer.

The Australian literature advocates the establishment of individual specialised cancer services in each state and dedicated adolescent cancer units for AYAs and their families (CanTeen and Cancer Australia, 2009; Herron, 2008; Palmer & Thomas, 2008). In recognition of this the Australian government has committed $15 million dollars over three years for the establishment of these centres and AYA cancer services (CanTeen, October 26th 2007; Herron, 2008).

Given the limited number of specialist cancer units world wide and the limited literature as to what are the benefits of such units and how should they be managed, the question remains as to what is the best model of care for this special population (Reynolds, Wineback, Leonard, & Wallace, 2005). Reynold et al’s (2005) UK quantitative study using the Youth Satisfaction Questionnaire found there was no significant difference for
adolescents treated in the Teenage Cancer Unit (TCU) to those treated in the adult and paediatric wards. The participants consisted of 68 adolescents; 30 from an adult ward, 15 from a children’s ward and 18 from a TCU. Although the TCU adolescents were more satisfied with the environmental aspects of care, the adolescents from the adult and children’s wards were dissatisfied with privacy, their say in care and treatment, and the access to school advice, peer company, hospital food and the noise level of the ward. The most significant difference was related to peer company, which was rated highly in the TCU and consistently poorly in the adult and paediatric wards. Allen (1997), when speaking about the cancer units established in the UK says the units have provided an ideal environment for investigating the psychosocial impact of cancer on the family. The units provide a place for the concentration of specialised services and the opportunity for both family and AYAs to talk to others on a similar journey. Although, as confirmed by Geehan (2003), if an AYA relapses and dies this can result in emotional distress for other AYAs and family members. Added to this is the possibility of dependency on the unit and its staff by the AYA and the family (Allen, 1997).

A UK qualitative study interviewed fourteen AYA cancer patients aged 15-20 years. This study determined that place was important in relation to the experience of AYAs and their families. There was a consensus that centres of excellence provided a sense of place in which the cancer landscape could be explored more easily. The AYAs summation of being in a place designated for AYAs was that the care was excellent, with the AYAs believing the staff were more attuned to dealing with the needs of adolescents and they welcomed the opportunity to be with other AYAs exploring the same landscape (Wilkinson, 2003). This study found sub-optimal care within the referring units with one of the family members describing being on the adult ward as “like I was in solitude or being punished for something I haven’t done” (Wilkinson, 2003, p. 69).

This importance of place and the settings of care for AYAs is further demonstrated in Grinyer’s (2007a, 2007b) UK study in which the AYAs were cared for in variety settings, both specialist and non-specialist. For the AYAs cared for in the non-specialised units, stress was exacerbated by the staff’s lack of understanding of the psychosocial issues for AYAs and their families. Being treated on wards with older people was seen as depressing, demoralising and adding to their feelings of isolation. The children’s ward was also not appropriate. Feelings of isolation and difference were
mitigated when treated in age specific wards, which improved the AYA’s morale. In addition age specific care made a difference to material circumstances. The age specific units maintained a connection with the normal everyday youth culture recognising the person’s age and life stage. The units also provided an environment where friends were welcome, even en masse. The expertise of the staff resulted in appropriate advice on issues such as fertility and appearance. The specialist unit also provided a team that facilitated the AYA’s return to school, and an activities coordinator to engage the AYA whilst on the unit. The benefits of being cared for in a specialist adolescent unit, was confirmed. Of particular importance was the central ethos of creating a culture of empowerment in the specialised unit (Grinyer, 2009).

The benefits of the specialised cancer unit are further confirmed by an ethnographic qualitative study by Kelly, Pearce, and Mulhall, (2004) and Mulhall, Kelly, and Pearce, (2004) to evaluate an adolescent cancer unit. The study identified the following categories associated with a specialised cancer unit. The physical structure and facilities: the unit created an atmosphere of enhanced normality; social context: the relaxed and friendly atmosphere provided a social context where normalcy was possible; family: there was an emphasis on the importance of the family and maintaining normal routines; what it feels like over time: key points in the cancer journey such as diagnosis, end of treatment and relapse were important for the cancer experience; cancer and the cancer unit: although the word cancer had negative connotations, the cancer experience was seen as a common bond for AYAs and families because ‘everyone was in the same boat’; and “specialism” and expertise: the availability of an expert team of professionals who intuitively understood AYAs cancer created a supportive environment. Kelly et al (2004) and Mulhall et al (2004) indicate that these combinations of factors create a therapeutic space of a relaxed and professional atmosphere with a more supportive environment for patients and the family.

Despite acknowledgement of this ideal model there is little information on what is the best strategy to provide this model of care. Ferrari and colleagues (2010) reviewed the experiences of AYA oncology programs in Europe, North America and Australia. This review acknowledged an ad hoc implementation of models of care that have evolved in response to local issues, variations in funding, medical culture and resources providing a diversity of models of care. The main factors which resulted in successful
establishment of dedicated AYA care was the involvement of both adult and paediatric oncologists, dedicated professionals advocating for these services and the philanthropic support of powerful charities. This suggests that the development of specialist AYA oncology services is, at present, not a priority for relevant governments of the AYA programs that were reviewed. The models which were reviewed were dependant on philanthropic donations, with only one out of six AYA programs in six international sites, (On Trac@PeterMac in Australia) being assisted by government funding. Added to this, only one program had dedicated AYA inpatient rooms, (Centro di Riferimento Oncologico Aviano in Italy) (Ferrari, et.al, 2010). At the time of writing this study, in Australia the Commonwealth Government has committed only $15 million over three years for the establishment costs of Youth Cancer Networks. This is despite the fact that the Australian National Delivery Framework and On Trac Practice Framework have recommended time, resources and money for the development of services for AYAs living with cancer (CanTeen and Cancer Australia, 2009; Palmer & Thomas, 2008).

A supportive atmosphere or place for the AYA and the family is significant, with the stories in this study telling of how important it was for family members to stay connected and supportive to the AYA during their treatment and hospital experience. This is also evident in Grinyer’s (2007a) research when she spoke of the importance of families for the AYAs in her study. She noted when collecting data for this study that “families were a characteristic and ever present feature of the specialist ward” (Grinyer, 2007a, p. 140). The professionals in the specialist unit noted the vital support they provide to their son or daughter. This involvement, according to Geehan (2003) reduces the parents’ feelings of helplessness, provides greater support for the AYA because of increased understanding, and helps the AYA develop a trust in the parents’ ability when they go home. This parental involvement is not always easy to negotiate, particularly if the AYA is treated outside of a specialist facility with some of the professionals outside the specialist setting in Grinyer’s (2007a) study indicating that dealing with the family could be problematic.

Within this discussion of therapeutic landscapes the places fall under two categories: those pertaining to extraordinary landscapes, such as hospitals which are located outside the person’s everyday life; and those representing everyday aspects of healing (English, Wilson, & Keller-Olaman, 2008). English, et al (2008) conducted semi-structured interviews with 14 breast cancer patients to examine the role of environments in shaping
healing. The study identified that the creation of therapeutic landscapes in the person’s everyday life requires a range of individual, family and community-based strategies. In particular, the emotional support provided by family and friends embedded within particular places such as home and community was important. The importance of family and friends and community in creating a healing landscape is relevant in this study. When the AYAs were discharged from the cancer hospital landscape, the normal everyday landscape was extremely important in the creation of a therapeutic landscape. This ability for a place to be therapeutic is referred to as ‘psychological rootedness’ where a person has a long standing relationship with a certain place, which is characterised by feeling of self identify and security. Such an environment is understood to be the personal home (Williams, 1998) and would also include the community in which a person is a part. This psychological rootedness was observed in this study with the AYAs return to the safety and security of their home, and their attempt to live life as normal as possible. They sought to engage with the community by returning to school or work and to engage in the normal social activities with their peers. This highlights the importance of the home and community as having a positive sense of place for the AYAs in this study, which Williams (1998) indicates has a strong positive effect on human attitudes and behaviour.

Ferrari et al (2010) have suggested an ideal model of care for AYAs and their families. This model emphasises the culture of care, a unique physical space, and provider expertise. The culture of care “recognises varying levels of developmental maturity and independent decision making, but acknowledges the need for navigation and support, especially around the psychosocial issues of emerging adulthood” (Ferrari, et al., 2010,p.4852). Despite acknowledgement of this ideal model there is little information on what is the best strategy for how to provide this model of care.

This discussion highlights the need to identify what is required for AYAs to create a therapeutic landscape in their cancer journey. In addition, it also highlights the need to identify therapeutic landscapes for the family members who are accompanying the AYA on this journey; this could be achieved by acknowledging the importance of the family within the AYA’s cancer landscape, and including family within the assessment of the AYA. More research is required into the developmental needs within a family system model for the family with an AYA with cancer. This would ensure that research
is based on a holistic model that incorporates important aspects of the AYA and the family when exploring the cancer landscape.

CONCLUSION

The experience of the family members in the Departure and Exploration stages of the AYAs’ cancer journey speaks of anxiety and fear as they sought to care for and protect the AYA within the cancer landscape. The initial signs and symptoms which resulted in the AYAs seeking confirmation of what was wrong were not seen as anything too serious, and for most it was difficult to comprehend that a person that young could have cancer. The confirmation was the start to the cancer journey, which at times was difficult to commence because of confusion about the diagnosis. Once the AYAs had crossed the threshold into the cancer journey, the family members sought to stay connected and supportive and this was, at times, difficult because of not having a full understanding of the cancer journey. This was related to how, when and to whom information related to the cancer journey was conveyed.

The hospital environment and the treatment that occurred in that environment were seen as an unauthentic environment, which further exacerbated their anxiety and fear. The AYAs were isolated in an environment in which there was no place for AYAs, whilst having to witness the suffering that occurs in such an environment. There was little understanding of the issues that concern AYAs and their families and the family members’ stories told of the difficulties associated with this. Furthermore the experience of watching their family member go through the effects of treatment, resulting in a sense of powerlessness and lack of control. The experience resulted in the family members strengthening their bonds with the AYA and attempting to be available and engaged with care wherever possible, which was sometimes difficult. Throughout the cancer journey the AYA demonstrated courage as they explored the cancer landscape and attempted to live life as normally as possible.

The themes demonstrated that the AYAs and the family members in this study have similar needs, as has been reported in other studies, although this study highlighted the experience for the family members in witnessing these needs as not being met. This was in addition to the sense of helplessness and lack of control, which were part of this cancer journey. The discussion in this chapter spoke of therapeutic landscapes and how
place contributed to a therapeutic landscape. The place associated with the AYAs cancer landscape has been demonstrated to be a non-healing place. Evidence that TCUs provided a therapeutic landscape for AYAs and their families was provided. The home and community, were seen as a place of psychological rootedness, which created a healing environment for the AYAs. Finally, it was recommended that more research be directed to the family system in order to understand and provide the best model of care for AYAs and their families.
CHAPTER SEVEN: ANALYSIS AND INTERPRETATION

THE META-NARRATIVE: THE DYING LANDSCAPE - DESTINATION

My mind careers like a spinning top across the nineteen years I have shared with Charlie. It ranges in loose loops round the first seventeen, then spins in tight concentric circles round these past two years since diagnosis. Spins first in impotent rage, then dissipates to anger, and finally winds down into sorrow --- sorrow that I cannot carry his burden of suffering for him, that I cannot not offer my life for his. Acceptance that I can accompany him just so far and no further on his journey: that is the goal I need to reach. My journey of submission.

My mind resists. Children outlive parents: aren’t I entitled to hold that innocent expectation? Isn’t that the natural order of things?

(Addison, 2001, p. 70)

INTRODUCTION

The previous chapter analysed, interpreted and reflected on the stories of the family members in the Departure, Exploration and Anticipation stage of the cancer journey. This chapter, using the same method of analysis and interpretation as the previous chapter, creates a meta-narrative for the final stage of the cancer journey - the Destination stage. The Destination stage for the family members in this study was a major turning point in which the family members and AYAs enter a different landscape to the cancer landscape; the dying landscape. The family members are required to deal with the reality that the AYA is going to die and does die. This knowledge is required to be assimilated and given some meaning as the family members witness the deterioration of their loved one until they reached their final destination.

This dying landscape emphasises a change in the focus of care as the family members support the AYA to their destination in our society. The dying landscape is a landscape associated with old age and a life well lived. For some of the family members and AYAs in this study the first encounter with this landscape is the dying and death of the AYA. An AYA’s relationship with death has been described as unexplored at worst and
conflicted at best, which can result in an existential crisis (Palmer & Thomas, 2008). This landscape is even more foreign than the previous cancer landscape as the family members assist the AYA through the dying trajectory to the actual death. Overall there were 12 themes and 34 subthemes within the Destination stage.

The themes associated with the dying landscape, the number of stories which contained the themes and the number of references within the stories to these themes are summarised in Table 7.1. Subthemes which emerged from the themes, which provided a deeper understanding of the experience for the family members, are also listed. (The table has been laminated and placed in a folder at the back of Volume 1 of this thesis as a quick reference for the reader).

**Destination: Narratives from the Dying Landscape**

“When did I last stop thinking of the future with you and me in same picture?”

Anthony Barling (2002)

**Theme: Ending the Reprieve**

Ending the reprieve was the theme that spoke of the cancer returning when the AYA and the family members had thought they could just get on with their life. They had been given the expectation that the AYA was in all probability, cancer free. The stories are similar to the Departure stage in which the family members spoke of noticing that something was different. Noticing that something was different resulted in the family members and the AYAs being informed that the cancer had come back.
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<td>Keeping a vigil</td>
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<td>Witnessing heroism</td>
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For Denise they were shocked with the discovery that Brenton James’ cancer had returned. They believed they had managed to get through the horrible time and were free:

[Brenton James told Denise that his stomach hurt] and it was discovered that he had a fairly substantial tumour in his liver, a secondary cancer from the eye, which was a great shock to us because we had been told that … they didn’t think we’d ever see them again and everything would be fine … So we went to visit [the specialist] and he … did say that there was no cure … it was more of a shock because we thought that we were going to be fine. You know we got through this shocking period of him losing his eye and we’d been given the all clear. We’d got through this, we’d escaped.

This is similar but different to Deborah who was always aware that Matthew Anthony’s cancer would return but became unconcerned as the tests were always positive:

So he continued on with his monthly checkups and CT scans and then we got up to two monthly and eventually we were at three monthly and almost about to go to six monthly when he had a really bad pain in his testicle. By this stage he was 17 … and we’d sort of got a little bit blasé about it all because the doctors kept saying “it’s a really aggressive cancer and you’re not going to beat this” … all his checkups they just kept getting better and better and there was no more hotspots showing up anywhere and he was doing really well … and, then he had this pain in the testicle … so I took him up to the local hospital … the next day we were down in Melbourne and told that it had returned.

For Lauren, she was concerned that Grant was weak and not getting any better. The news was devastating when they found a tumour in the lung:

five months … he wasn’t getting better and it was frustrating me [I was thinking] why, why isn’t he better? He was still very weak and just really unwell still wasn’t able to eat and I’m thinking what is going on? … Then in the April he started coughing and we called the oncologist and they said it is probably just a virus … but we will get an x-ray just in case and that is when they found the tumours in his lung. So that was pretty devastating.
Tamina’s reprieve ended when she relapsed with Ewing’s sarcoma. Pam spoke about how the system was slow to respond to Tamina’s cough. When a different doctor did respond and ordered chest X Rays they discovered she had relapsed with Ewing’s sarcoma:

we’ve been coming back and forth, or Tamina had been for a few months with this cough … She was told she had a lung infection … She had a file that thick because he had all of her medical history in it and nobody cottoned on to actually send her for a chest x-ray and that day … she saw a different doctor and she was coughing when she walked in, and he said, oh I don’t like that cough. It was a terrible cough … we found out that she’d relapsed … I’d seen the x-ray and I knew what they were going to say.

REFLECTIONS ON ENDING THE REPRIEVE

For those family members whose AYA went into remission, the sensing of a reprieve and the beginning of the restitution narrative ended when the AYA relapsed. This return would once again see the family members living the chaos narrative as they seek to create meaning from the experience. The return of the cancer was similar to the diagnosis phase when it was noticed that something was not right. This return was associated with pain, noticing that the AYA did not appear to be improving or physical symptoms such as a cough. The family members in this study who had been given a reprieve had all believed they had left the cancer landscape behind and were busy getting on with life. Unfortunately, this time in their familiar landscape did not last. They were once again confronted with the reality that they were required to return to the cancer landscape. This time the landscape was more frightening and unfamiliar as they were confronted with the reality that the cancer had spread and the possibility or inevitability of death. All these stories speak of the shock and devastation on hearing that the cancer had returned.

In most of the stories the system was quick to pick up the return of the cancer with the appropriate diagnostic tests. Although, this is different in Pam’s story, that suggests a lack of communication, coordination and understanding of Tamina’s previous cancer journey.
One explanation for this lack of coordination of Tamina’s care was her transition from the paediatric system into the adult system. Viner (1999, 2003) has described the fate of older adolescents in the paediatric system as; staying in the paediatric system, transferring to the adult system or being discharged from medical supervision either voluntarily or by neglect. Viner (2003, p. 2684) advises that “attention to transition is important to prevent gaps in health care, either at the end of treatment or during long term follow up” . Transfer to adult services is not enough. The older adolescent requires comprehensive transitional planning to take place (Viner, 2003). This lack of transitional planning can result in a person arriving in a new service that is unprepared and ill informed. Added to this is the possibility that, because of their age, they may drop out of the medical system and only make contact in times of emergency. This is particularly relevant to cancer survivors where irregular contact may result in a delay in confirming a reoccurrence and the detection of secondary tumours (Viner, 2003). The fact that the system was slow to pick up on her previous cancer and interpret her coughing as a possible reoccurrence of the cancer, suggests that this was the case for Tamina.

**Theme: The Pronouncement of Impending Death**

The dying landscape involves the AYA and the family members being aware that the final destination is death. Naturally being informed that death is inevitable would be difficult to hear and to fully comprehend. Susan Addison’s (2001) quote at the beginning of this chapter speaks of the natural order of things and her mind protesting as the natural order of things includes children outliving their parents.

The theme pronouncement of impending death was in response to the family members’ realisation that their family member was going to die. For some this pronouncement was when they were told that there was nothing more that could be done, while for others the pronouncement did not occur until the AYA was close to death.

**Being Told**

For Denise it was with frustration because the young doctor was not direct about Brenton James dying:
the intern doctors … a lot of them are still finding their feet with how to deal with these things … especially the one that was trying to tell me that my son was critical and that he would die, he rambled on and on and on and on, and I wanted to shake him. To say … just say it … [I] know what you’re trying to say, but I didn’t.

This was a different experience to Fulvia who remembers the doctor explaining how and when Jadye would die so they would not be frightened of the process:

we all stayed and the doctor came in, a female doctor … and said in front of everyone, “Jadye’s condition has deteriorated, Jadye’s now unconscious and soon she’s going to start cheyne stoking, she’s going to start breathing different and so on and I don’t want you all to be distressed, it’s just the normal way of dying, there’s no pain and she’s not in any distress” … she said “it could take a day or two before she passes away” and we went, all right.

While for Jenny, rather than tell her face-to-face that Brenton Duncan was going to die she was told by phone at work. She had to tell him herself that he would die and he responded with courage:

the doctor rang me at work and said to me: “I'm sorry, but Brenton is going to die, we can't do anything about it. He has got metastasis everywhere” … so, I just came home from work and we didn't know how to tell him, but I think he knew anyway … We said to him that night: “Brenny, its come back, you've got metastasis”, and he said: “Yeah I’m going to die, aren’t I mum”. I said: “Yes love, you are”. And he cried. Then he said: “Mum, I'm going to be okay don't you worry about me”.

Whilst Jenny was able to inform and support Brenton Duncan when she told him he was going to die, Tamina did not want Pam to go into the doctor’s room with her, which made it hard for Pam. Pam said she was told without any support:

I think she just didn’t want to upset me and the last time she saw a doctor about 4 weeks before she passed away, she wouldn’t let me go in. I wanted to go with her and she said “no, you’re not coming in.” When she came out …
I could see she’d been crying. I said, “are you all right”? She said “yes I am,” she said, “that doctor told me I’m going to die.” Just like that … I just think that’s awful that the doctor just told her that. She was in there for a while and he told her she was going to die … and they knew I was out in the waiting room.

Response to Pronouncement

When Mick was told there was nothing more they could do, he responded with denial as he still believed he wasn’t going to die:

the doctors came to see him in Newcastle after the last lot of chemo … they said “Mick, there is just absolutely nothing more we can do. We’ve tried everything, we’ve searched the internet, we’ve searched everywhere. There is nothing more it’s just coming back too quick.” He said, “how long have I got,” and they said, “they don’t know, it depends how quickly your white cells rise”. And he just looked at them and said, “I’m not going to die. I don’t feel like I’m dying” … he was still as stubborn and determined.

For Lauren, she responded by asking questions. She believed the medical profession had given up and there was nothing more they could do and that felt horrible:

my mind it was just turning over all the time, like what about this, what are our options, what can we do … why is this happening, why can’t we do that blah blah blah. And Rick was fantastic he spent an hour answering all my questions … knowing that … the medical profession had given up on him in a way, not that they had in terms of giving him the best treatment that they could while they could but the fact that that’s it, there is nothing more we can do for you was horrible.

This has some similarities when Naomi was told it was terminal; Rebekah was really frustrated and angry and wondered when do you decide it’s not curable:

at the very least you don’t expect it to happen so quickly, from the point of diagnosis to … it’s not curable … I was really frustrated and angry about it … when we were told she was terminal. I said right, so she was curable right up to the point that you can’t do anything, it’s curable, it’s curable, it’s
curable, ooops, it’s not curable … why didn’t you realise that months ago.  
You know it’s just … frustrating in that regard.

**REFLECTION ON THE PRONOUNCEMENT OF IMPENDING DEATH**

Similar to being informed about treatment, the way the family members were told that the AYA was going to die made a huge impression on how they managed to incorporate this information. Once again these stories speak of problems with health care professionals communicating bad news. Denise found the experience very frustrating. It is interesting that this pronouncement of impending death was given by an intern who was just finding his feet and, as such, had not had the experience or expertise in communicating bad news. This awkwardness made a distressing situation even harder to deal with. This is in contrast to Fulvia, for whom the dying process was explained compassionately. The fact that Fulvia was aware of the process and what to expect no doubt made a difference to how she negotiated the dying landscape.

In two qualitative studies (Wee, Coleman, Hillier, & Holgate, 2006a, 2006b) interviewed 27 bereaved relatives to investigate their response to terminal care and their interpretation and response to the death rattle. The first study found that some relatives are distressed by this sound (Wee, et al., 2006a). This distress appeared to be associated with the relative’s interpretation of the sound. A distressing interpretation was associated with whether they believed the relative to be suffering or not (Wee, et al., 2006b). These two studies provide support that the way Fulvia was told about the dying process would have influenced her interpretation and probably caused less distress as she witnessed Jadye die.

Both Jenny and Pam’s stories demonstrate once again a lack of sensitivity in breaking bad news. As with the Departure and Exploration stage of this study, the health professional failed to communicate devastating news with compassion and care, demonstrating a limited understanding of the impact that such information would have.

This lack of empathic communication can be explained as clinicians being frightened to talk about death with AYAs and their parents, as death of a young person is often interpreted as a failure (Palmer & Thomas, 2008). Pazola and Gerberg (1990) say communicating that death is imminent can be done gently, with supportive
communication, providing the opportunity for the AYA to share their feelings. These feelings can range from anger, crying and withdrawal and requires supportive people who can tolerate uncomfortable feelings (Pazola & Gerberg, 1990).

The family members and the AYAs in this study had various responses to being told that there was nothing more they could do. Mick’s response is one of denial, which has been identified as a universal response for adolescents confronting a terminal illness (Freyer, 2005; Klopfenstein, 1999a). This denial is at times an attempt to protect the family (Pazola & Gerberg, 1990). Pazola and Gerberg (1990, p. 17) have said that “when patients sense a caregiver can tolerate the powerful sadness, they will often seize the opportunity to vent their thoughts and feelings”. Mick did not have the opportunity to discuss his imminent death. It is hard to know why he sought to deny his imminent death, whether it was a coping strategy that worked for him or if it was to protect those he loved. The opportunity to engage in any in-depth dialogue did not appear to present itself in Mick’s case.

The responses from Lauren and Rebekah provide support to the death of a young person being interpreted as a failure and how difficult it is for clinicians to determine when care is palliative, with one paediatric oncologist saying “with young people, going for a cure is such a major thing that referring to Palliative Care can have a sense of ‘giving up’” (Palmer & Thomas, 2008, p. 68). Lauren and Rebekah support this statement with Lauren thinking the medical profession had given up on Grant and Rebekah wondering at what point did they decide that Naomi was terminal.

Of note, in response to the pronouncement of impending death when the family members and the AYA were informed that the AYA was about to negotiate the dying landscape, there was not the same confusion as when the family members had previously departed from their familiar landscape to explore the cancer landscape. Whilst they knew they were entering an unfamiliar and frightening landscape, there was little they could do about the outcome except stand by and patiently wait for the final destination of death in the dying landscape.

**THEME: CHANGING THE FOCUS OF CARE**
For the family members in this study there was a stage in the cancer journey, when they knew they were entering the dying landscape, they noticed a change in where and how treatment or care was delivered. Changing the focus of care is when the family members observed this change. For some this changing the focus of care was where the care was delivered, for others it was how the care was delivered.

**Deciding Where the Care Would be Delivered**

Irene spoke of Thomas staying home for the end, which she thought made it easier for the family:

> they told us then there was nothing else they could do. He stayed home. So he had a lot of treatment at home … he wouldn’t stay in hospital for the last … we could pop in and see him any time we wanted to, sit beside the bed and talk to him. … on a weekend you’d go into Thomas’ bedroom and there’d be mattresses all over the floor where they’d[his friends] all stay … In the end we bought Thomas a little bar fridge to keep next to his bed, so he could keep himself some cold drinks of water without him having to struggle to get out of bed, because it was a big effort to get out of bed and reach for the crutches … we moved him from one bedroom to another, so we gave him the bedroom with the ensuite … So we tried to make things as good as we could for him … With the hospital you couldn’t all be there … they’ve got their restrictions and it wasn’t fair to other patients you know. Yes I think it was better for him to be at home. I think if any kid’s going to go through this, stay at home if you can get treatment at home rather than be in a hospital.

This is different to Brenton James who wanted to go back to Peter McCallum because he felt safer there:

> he was only home a couple of days and then he started to get a temperature … and his specialist said … “we want him back in Melbourne.” Brenton and I wanted to go back too because he felt safe there. He had struck up a rapport with a special nurse there who … was a local girl from the town just down the road from us, so he felt much safer to be back there.
This is in contrast to Jenny who found it difficult when the focus of care changed; she said there was no place for Brenton Duncan to go. The Children’s Hospital abandoned them and wouldn’t take him and the Hospice was for older people:

we never had very good support through the Children’s Hospital when he was dying. I asked could he be admitted there when I couldn't cope for a night and day. They really wiped their hands of us, “we only want children that we can cure or we can help but he is dying so no” … I said “where else can he go?” And there were no answers … They did offer the hospice around the corner here but I went around to see it and it was just full of old people and I couldn't put my son there.

Kerry also found deciding where the care would be delivered difficult when she was informed about palliative care, which felt like going to a cemetery and looking at a grave every day:

the doctors … they told me about the word palliative and that, you know you’ve always thought palliative was a care … So it goes with kindness because that’s what caring is, caring is nice and soft and lovely. But it’s not, it’s actually where you go when you’re dying … I said not to say that word, it makes me nearly vomit. It’s like going to a cemetery and looking in a grave every day. That’s how disgusting it is to go there every time and that was Alinta going there.

Deciding where the care should be delivered was difficult for Deborah when Matthew Anthony decided he wanted his care to be given at home, particularly when he asked to go home to die. The doctor at the hospital did not want him to go home and Deborah had to insist that he be allowed to go home:

Matthew had actually said “I don’t want to keep coming to Melbourne. I’m sick of it, I just want to be at home with my family and my friends.” And they didn’t want that, they kept saying “no, no we have to keep seeing you. We have to do this” and in the end Matthew just point blank refused … and when Matthew said he wanted to die at home and not in hospital, the doctor almost laughed at him, and said “well, that’s just ridiculous” … Matt said, “well I want to go home, now,” and she said, “no you can't go home now,”
and he said “I’m going home now. Mum tell them I’m going home. I’m not going to die in hospital. If I’ve only got a week to live, I want to be at home,” and they wouldn’t let him go … and I just said “well, we’re going home. I don’t care what you say now, Matthew has expressed his wish to go home. You said he’s going to die, there’s nothing more you can do for him, we’ve got scripts for his morphine and … all his medications. We’ve got the stuff, we’re going home and he will die at home.”

Unlike Jenny who found the option of a Hospice not suitable for Brenton Duncan, Sue’s option was to transfer Ben from the acute hospital system to Calvary Hospice, and although Ben knew he was going there to die he was able to create his own space in the private room:

anyway he rallied … so they said, “how about we change him to Calvary,” which is near us … It was a hospice … and Ben said, he said “yeah, I’m not going to come home” … Calvary is only 15 minutes and so he reluctantly went down there … and then they moved him into another ward, which was even more special, and one of the nurses … she said that “they only put very special people in that room” … and they said “look, you make this room yours,” so everyone who came in, all his friends, would bring pictures, so the whole wall was full of photos … and CanTeen made a big banner for him. They all signed that and he had that, until the day he died.

How the Care Changed

Lauren remembers the quality of care didn’t change, just the focus of care changed to ensure a quality of life for Grant while he was dying:

I don’t think the quality of care changed only the focus of the care changed. So, whereas in the first time it was, well it doesn’t matter how sick he gets because the end … he’ll be alive. After that, it was like we don’t want to make you too sick we want you to enjoy the time. So, we want to make you sick enough that you can be well enough for a while and then you know … deal with it again. It was constantly weighing up the pros and cons of each lot of treatment, whereas before it was just do it … as long as you get through it … and so that really changed … it definitely didn’t feel that the
medical profession treated him as a possibility, it was more a matter of when he died and how are we going to make from now to when he dies better than trying to prevent him dying.

For Alan he noticed the change in the focus of care when a young resident doctor advocated, in the emergency department, that Naomi not have all the tests and scans because she was terminal:

emergency doctors tend to be what they are, wanting to know all the ins and outs and everything else, they were wanting to do all of these scans and tests to see why she was having shoulder tip pain. Helen [resident doctor] told them that she was terminal but they were still persisting in wanting to do that and apparently Helen said, “you’re not doing that … you’re not touching her” and persisted … so they backed off.

Changing the focus of care and not subjecting the AYA to further tests and scans was even more evident for Val when she was asked if she wanted Anthony Charles to have any more treatment, which she knew would cause more suffering:

in the last 4 days he was very well aware that he was dying … 4 days before he died the specialist sat down with myself first, and said did I want him to have any more treatment, they could keep him alive for another 3 or 4 months if we so wished, and I said to [the specialist], “what … for?” I said, “he’s been through enough already” … it was an easy decision, because why put the poor kid through so much more turmoil and hell than what he’d already been through, and who was it for, me or him? If I kept him alive it’d be for me.

**Reflection on Changing the Focus of Care**

Once the family members and the AYA were aware that the AYA was dying there was a change in the focus of care. This change in the focus of care was both where and how the care was delivered. The place of dying varied within the stories, some choosing to be cared for at home others returning to the hospital, others having palliative care
involved while others felt there was no where for the AYA to go and, because of this, had limited choices and support.

For Thomas, dying at home was considered the best place to die. This decision to die at home is reflected in the literature with most people believing that dying at home is the preferred place (Bell, et al., 2010; Foreman, et al., 2006; Grinyer & Thomas, 2004; Hinds, et al., 2004). In Foreman et al’s (2006) survey this strong preference to die at home was particularly relevant in younger people. Grinyer and Thomas (2004) believe the alienating hospital experience contributed to the young person’s wish to die at home. This is supported by Hannan and Gibson’s study where the childrens’ decision to die at home was related to negative hospital experiences. The parents wrote of how a home death provided the opportunity to be surrounded by family and friends and provide a sense of normality where the family life could continue (Grinyer & Thomas, 2004).

Although not all AYAs in this study chose to die at home; Brenton James wanted to go back to Peter McCallum. For Jenny, the decision for Brenton Duncan to die at home was based more on necessity rather than choice. It is not evident if Jenny wanted Brenton Duncan to die at home, or if she would have preferred him to die in a more controlled environment. Jenny described a lack of support for her in Brenton’s dying journey at home.

Most young people say they wish to die at home (Bell, et al., 2010; Foreman, et al., 2006; Grinyer & Thomas, 2004; Hinds, et al., 2004), the decision to die at home has been associated with contributing to the overall quality of peoples’ lives, facilitating a sense of normality, security and personal control (Morris & Thomas, 2007). On the other hand Williams, et al (2002) suggest that dying at home can be associated with struggle and a place of physical, emotional and organisational labour.

Morris and Thomas (2007) highlight, that the place of death is more complex than assumed, with the social relationship of the carer playing a significant role in the preference of place of death. The literature suggests that this struggle and lack of support has been associated with families not having the ability to care for the AYA at home and care continuing within the hospital system (Zelcer, et al., 2010).

This lack of choice and the decision to care for the AYA at home was further reinforced by Kerry’s story when she spoke about palliative care. The association of the words
palliative and dying made it difficult to acknowledge that palliative care was there to provide support. At the other extreme Deborah had to fight to ensure that Matthew Anthony could be at home and in particular that he would die at home. Sue’s experience of the hospice and palliative care to support Ben through the dying journey was positive. This was facilitated by the compassion of the staff and Ben being able to create his own therapeutic space.

The therapeutic place provided by a hospice is confirmed by Grinyer and Thomas’s (2004) study in which they found that if the dying was handled with sensitivity and respect for the AYA’s individuality, and comfort was provided for the parents, the death was less traumatic. This was further reinforced by Klopfenstein (1999) who described the hospice environment as a place that empowers the AYA to make choices. These five stories demonstrate the importance of the place of death although in this study the family members felt there was limited choice in where the AYA would die.

Gomes and Higginson (2006) reviewed the literature to identify the different factors which determined place of death. Of these one was the formal health care services available in the local area and, in both Jenny and Kerry’s stories, they believed there were no health services which could adequately provide the care for Brenton Duncan and Alinta, with Jenny describing the Hospice as full of old people and Kerry describing palliative care as like a cemetery. This belief may be overcome if the referral process from the curative system to palliative care is handled with sensitivity.

Ronaldson and Devery (2001) Australian qualitative study examined the experience of transition to palliative care from the perspective of curative and palliative care nurses and patients. The patients required time to assimilate that the focus of care had changed and this often does not occur, due to quick referrals to palliative care as a result of the pressure within the curative system. Within this context the patients were often not included in the decision making process. The suggestion of transition to palliative care was associated with fear and misunderstanding as most patients associated it with imminent death. Overlaying this was the reality that the patients’ believed they had no real choice in their transition to palliative care. Added to this reality was the fact that few patients had relevant information about what palliative care was and many only received this information when they were transferred to a Hospice. Of importance was the acute care nurses not being fully aware of the breadth of services available in palliative care. This study suggests that the limited choices that Jenny, Kerry and Sue
experienced may have been a result of not enough information, and lack of coordination from the curative to the palliative system of care.

Stillion and Papadatou (2002) suggest other barriers associated with the ability to choose a place to die includes an unwillingness to give up on a possible cure, an inability to cope with the dying experience, and isolation and helplessness in communities where hospice care for children does not exist.

The previous accounts tell of the importance of having a place and a space for the AYA to die. Within this space is the care that is provided to the AYA and which can provide a dying landscape that is sensitive to the needs of the AYA. In this study the stories told of how the care changed within this place from curative, aggressive treatment to care that focused more on the quality of life. This progressed to the family members focusing more on the quality of time that was left and protecting the AYA from further painful procedures and treatments in order to prolong life. There were some exceptions as noted in Naomi’s case where the doctors wanted to subject her to more tests and procedures.

All these stories reflect a change in focus not only from the medical profession but also from the family members. All the family members had accompanied the AYA on their cancer journey and had witnessed the ‘horror’ of treatment and the pain and suffering which could possibly result in a cure. This theme demonstrates an acceptance of a change in care and wanting to limit this pain and suffering. The literature review found that this change in the focus of care was not always evident, particularly for children dying from cancer in which aggressive treatment is maintained until the end (Bell, et al., 2010; Drake, et al., 2003; McGrath, 2001a, 2002a; Wolfe, et al., 2000). This maintenance of aggressive treatment has the ability for AYAs and family members not having the opportunity or time to communicate about end of life decisions (EOL) decisions (Wolfe, et al., 2000).

EOL decisions are the hardest part of the cancer journey and require time and information (Penson, et al., 2002). Effective and compassionate communication with children and their families is associated with high quality end of life care and the establishment of realistic goals (Hurwitz, et al., 2004). Changing the focus of care, as experienced in this study, made it easier for the AYA and the family to continue through the dying landscape, suggesting that AYAs and their family members should be
provided with the opportunity to discuss EOL decisions especially with respect to how their quality of life can be maintained during the Destination stage.

**THEME: GOING DOWNHILL**

The theme going downhill is how the family members noticed that the AYA was not getting any better and observing and trying to manage their deteriorating condition. The way the family members noticed the AYA was going downhill included, *the cancer has taken over, living with the symptoms, and being overwhelmed with pain.*

**The Cancer Has Taken Over**

The start of noticing that the AYA was going downhill is when the family members become aware that the cancer had spread and could not be contained.

Denise remembers for Brenton James the cancer had taken over when he had the look of someone dying:

> his liver started to swell, and they said “well that’s a good thing, it’s doing what it should be,” but then it continued to swell and … his stomach became bloated. His legs were full of fluid, the rest of him was fading away and he was having increasingly that look of someone that has not got long to live.

For Fulvia it was the return of the cancer after the bone marrow transplant:

> they took her bone marrow and they gave her bone marrow transplants … after the bone marrow they said that … “there’s a little bit in her liver and we’ll do radiotherapy for the liver” … Within a week it was in her liver, in her lungs, in her back, in her shoulder and in her bone marrow, horrible cancer. It’s cruel.

**Living with the Symptoms**

Living with the symptoms for Cheryl involved having to devise a different way to communicate with Paul Malcolm as he became blind, deaf and very frail:

> They didn’t expect it to happen as quickly … Paul became blind and deaf and very, very frail … and as he became blind, we would find other ways of
communicating with him, and that was very difficult for other people on the ward because we were doing a lot of shouting. We were apologising, but at the same time what do you do? This is my son I’ve got to communicate with him.

Helen and Geoff noticed nothing seemed to work properly any more after Mick’s potassium levels went so high. He had seizures, which broke a couple of vertebrae in his back:

he had that attack with the potassium levels going so high everything just seemed to not work properly any more. He was swollen up so badly and he had … 2 or 3 really bad nights … like an epileptic seizure, they tended to think that it had gone into the brain and … [he] broke a couple of his vertebrae in his back when he was having seizures … so it was pretty uncomfortable.

Sue found dealing with the seizures, when Ben’s melanoma metastasised very frightening:

he actually had a couple of seizures too, which were pretty bad … It’s just frightening. My sister’s epileptic so I had seen it before … but when it’s your own it’s just horrendous and you’re powerless, you can’t do anything.

For Kerry living with the symptoms was dealing with the neurological deterioration that she hadn’t expected:

she was restless at night. You have brain things … you might have fits … there’s agitation and fidgets. It was agitating for her. She was biting things, she was doing this, she was uncomfortable, couldn’t talk.

**Being Overwhelmed with Pain**

For Fulvia going downhill was associated with having to take Jadye to hospital because of the pain. Once she was in hospital it was accepted that Jadye would not go home:

we sat up for night after night with her screaming and all these tablets I could give her and then the next morning when she woke up she had a black eye, all her arms were bruised, she had bruises coming up everywhere …
and she didn’t want to move, and she just begged me, “no leave me at home, leave me at home” and I yelled at her and made her go to the hospital and she never came home … and the first night … she was in pain and they had her drugged up … then … she sort of wasn’t herself … she was not with it … they said she was too ill, to bring home again and she was too ill to move to palliative care. [The social worker] called me again and said, “Jadye’s not coming home” and this time I knew and we [Fulvia and Jadye] talked about it for a long time … and not long after that she just laid down and she was unconscious and she sort of accepted it.

Similar to Jadye, Brenton Duncan started to go downhill when he experienced sudden, severe acute pain, but rather than taking him to the hospital they brought him home. From then on Jenny watched him deteriorate:

[He was at his girlfriends place] he was lying on the floor and he said “nobody come near me I just need something to knock me out I’m in so much pain”. It came on him really quickly because that morning Jadye [Brenton’s girlfriend] said “he was fine like he hadn’t complained about being like this”. Anyway, he was screaming in agony and we got the district nurse to come around and give him morphine … they put a driver into him and then they brought him back to my house and we put him to bed and we will be able to look after him … and then he started trying to get up a lot because of the drugs, he got out of bed and he was falling over things. We had to shave him, and he just couldn’t do things for himself any more and he drank out of a baby’s bottle in the end because he couldn’t feed himself because he was so sick.

**Reflections on Going Downhill**

As part of arriving at the final destination on the dying journey, for most cancers this involves the spread of the cancer to other organs of the body. This experience was difficult for the family members to witness. Denise and Fulvia describe this process as horrible and cruel. Both vividly describe the deteriorating physical symptoms and realised that the cancer had spread throughout the body.
As both Denise and Fulvia observed that the cancer had spread, they also realised that their AYA did not have much time to live, they were not improving. The family members thought of ways to manage this deterioration, whilst at the same time having to watch the AYA’s suffering and pain.

For others it was not the symptoms that they had to deal with but overwhelming pain, which reinforced realisation that the AYA was going downhill and was dying. Also the pain relief medication affected the AYA’s functioning and ability to care for themself.

As with watching the inevitability of treatment all these stories speak of the powerlessness that the family members felt at witnessing the suffering of the AYA’s journey to their final destination. All the stories give graphic description of watching this going downhill with adjectives such cruel, horrendous, frightening, phenomenal and uncomfortable. Once again the sense of being out of control and the return of the chaos narrative occurs. All the stories spoke of the powerlessness at being able to manage the symptoms. This is confirmed in the literature review wherein parents observed their child endure sustained suffering during the last month of life (Anghelescu, et al., 2006; Hinds, et al., 2004; Wolfe, et al., 2000), and the parent’s dying trajectory is associated with uncertainty and apprehension (Monterosso & Kristjanson, 2008). Wolfe et al’s (2000) study confirmed that symptoms management was seldom successful. Anghelescu at al (2006) advocated a more holistic approach to palliative care as a way to clearly provide appropriate care and symptom management when dying.

**THEME: KEEPING A VIGIL**

As noted in the Exploration stage the family members in this study sought to be a constant presence for the AYAs on the cancer journey. This was even more evident within the dying landscape where the family members, particularly the mothers, stayed with the AYA 24/7. As such, keeping a vigil involves the family members staying connected with the AYA and ensuring they were not alone. As with staying connected and supportive in the Exploration stage, keeping a vigil involved sacrifice and the opportunity to strengthen existing bonds.

**Being There**

For Arlene keeping a vigil involved not sleeping in case Matthew James died:
I discovered you can actually go five days without sleeping. You think you’re making sense but probably the people around you don’t. I did not sleep a wink for two nights because I kept thinking what if he dies [while I’m asleep] and I only dozed at various times before that.

Shane spoke of the admiration he had for Grant’s mother who was with him 24/7. She slept in a recliner at the hospital:

*his mum was such a strong Mum and looked after him so well … she was up there like 24/7 at the hospital whichever hospital it was at the time. I didn’t have the strength to do that. I’d go up there and spend a few hours. …. And I felt sorry for Pam or admired her for just being able to keep going … constant … everybody knew her, she had one of these chairs, like a recliner, she’d sleep in those.*

For Sue keeping a vigil was also difficult at the time Ben was dying as one of her daughters and her husband were in two different hospitals:

*So I was going between Ben and George and Kellie Ann, but I knew I had to do it and something was driving me constantly. I couldn’t leave Ben and even though he was asleep sort of in the last few days, I would say to him, “I’m going to see your Dad. I’m going to see Kellie Ann, I’ll be back in an hour” and I was, I practically ran, but I knew I had to see them both and be back … but I knew I had to do it and I couldn’t leave him. But I was there for him all the time and I just hope to God he knows that that he knew I was there for him.*

**Strengthening Relationships**

Dying not only involved being there for the person by the family members’ physical presence but for some it strengthened the bond and relationship that the AYA had with others.

In Denise’s story strengthening the bonds involved her and Brenton James understanding they were on a journey together in which they were going to support each other on the way:
so for both of us there was just the two of us and we had always been extremely close and he started to depend on me a lot for everything ... we were on a journey that neither of us wanted to go on but nevertheless we were going to go on this journey together and we were going to support each other along the way.

For Deborah strengthening of relationships involved her watching the special relationship that developed between Matthew Anthony and his sister (Lauren) in the last month:

but the last month there was an incredible amount of bonding ... there's 19 months between him and Lauren. He was older, and to watch the relationship between those two develop ... Like they were all fairly close anyway but it just went further ... like he’d have his back to her and she’d lay on the bed and she’d massage his back ... and he’d end up going off to sleep and he didn’t ask her. She just did it and just watching that develop between the two of them was just beautiful ... even more, it just moved onto a much deeper level ... it was just beautiful, absolutely beautiful.

**Reflection on Keeping a Vigil**

Associated with the AYA going downhill was the time and commitment that the family members made to ensure they were with the AYA throughout the dying journey or the theme keeping a vigil. These stories speak of the family members’ great sacrifice as they tried to create a healing place; a place where the AYA could feel safe and cared for as they prepared for the final destination. Creating this place was exhausting for the family members as it involved lack of sleep, exhaustion and not being able to attend to the everyday. Added to this was the realisation that the AYA was dying thus creating extra stress. Other stories in this study also speak of having to sleep in uncomfortable chairs in order to be there for the AYA. Sue’s story speaks of the commitment and drive to keep going, despite the effort required to be there for Ben, due to other family crises, highlighting the intense bonds that keep the family member committed to the AYA.
This keeping a vigil not only involved being there 24/7 with the AYA, it also provided the opportunity for these intense bonds that had been established to be strengthened and deepened. The strengthening of these bonds provided the family with an opportunity to once again demonstrate their commitment and love for each other as the destination became closer. Denise and Deborah’s stories speak of the ability, despite the powerlessness and exhaustion associated with the dying journey, to still develop relationships at a much deeper level.

**Theme: Experiencing Lack of Care**

The previous two themes demonstrate the commitment and love that the family members had for their dying AYA, and the sacrifices they were prepared to make to ensure that the final destination was one in which the AYA was aware of the love and commitment the family members have for them. In order for the journey to be less stressful the cancer landscape requires the compassionate care and support from those responsible for providing care. Whilst this was evident in most of the stories, some of the stories spoke of a lack of care. Within the theme experiencing lack of care, the majority of these references were in response to the family members feeling that the system did not understand the AYAs needs or try to accommodate these. For others, feeling unsupported resulted in the family member feeling lonely and isolated.

**Lack of Care in the Hospital**

In Rebekah’s story this lack of care encompassed some of the standout things that shouldn’t happen in a hospital. She spoke in particular of the rough handling by a nurse, which caused Naomi pain:

> there was some stand out things [which] shouldn’t happen in a hospital, particularly with cancer and terminal patients. You know on the last night … everything was shutting down … she was all sore down one side of the body basically, the left side, and she was in a single room … we’d help her to the toilet … and then we needed help to take her back … so we called for the nurse … and took her back to the bed and because Naomi was so sore, she was just waiting … and the nurse [said] no no no, come on we’ve got you
get in bed and just grabs her legs and swings her up onto the bed and Naomi was crying in pain and then she, she pulled the blankets up and left. I was sitting there thinking … all she had to do was wait a minute so Naomi could catch her breath and get ready because she knew it was going to hurt.

**Non-Support in the Home**

Jenny experienced lack of care when she felt unsupported when caring for Brenton Duncan dying at home. She found it hard and would have appreciated time out:

> I know he wanted to die at home … There was no support there for anybody really … It was an awful time because it was just so higgledy-piggledy, there was nothing in place … I'd ring the Children's Hospital and they'd say “we'll put you on to the pain relief people”. And you think well okay but this is not what I need. I needed to have somebody to help out with everything but there wasn’t that help … he wanted to die at home so I wanted him to be with me but I just needed a respite every so often because it was very hard work when you don't know how long it is going to take, it's just all really really hard.

This is similar to Kerry when talking about caring for Alinta at home where there was no one to direct the management of Alinta’s care:

> doctors come and go and you talk to them for five or ten minutes … wouldn’t it have helped to have someone to oversee our whole care … just do it for us, really that’s what should’ve been happening. If she was in hospital, someone would be looking after her.

Kerry had been told to go home as it was the best place for Alinta, however there was no help and Kerry felt overwhelmed:

> so there was no choice as far as I could see, that someone had given me a 24 hour watch, with no help … I don’t understand why that was, that I had to go home and look after her. They're telling you that’s the best place but where was the help? They just told me to take her home. Now that's ridiculous.
This lack of choice and having to carry out palliative care in the home resulted in Kerry feeling isolated and more or less like she was in a prison:

"your life’s just so hard already. It’s just so hard and you get more and more isolated because palliative care is in the home … so you’re isolated, you’re it … it’s devastating and you’re isolated. You’re more or less in prison, really."

**Responses to Non-Support**

This was in contrast to Sue who knew she couldn’t cope with Ben at home, because she couldn’t lift him, and he returned to the hospice where they couldn’t do enough for him:

"Ben came home and he was home I think, two days, and he had a fall, his legs gave way, and I knew then he had to go back to hospital because I couldn’t lift him. He was taller than me and my husband was sinking deeper and deeper into depression, so I knew I couldn’t depend on him, so we got him back into Calvary and the people there are just angels, just fantastic. They couldn’t do enough for him, he was in his own room, they bent over backwards to get the food he wanted and they were just so caring and the room was bright, we overlooked Botany Bay."

**Reflections on Experiencing Lack of Care**

As can be appreciated, keeping a vigil was hard work and involved sacrifices from the family member. In order for the bonds to be strengthened the family members required a therapeutic space for this to occur. To be able to maintain this therapeutic space the family members required the care and support of health care professionals. As seen in the previous stories this was not always the case.

Rebekah spoke of the lack of care demonstrated by a nurse. This story speaks of insensitivity to Naomi and a lack of compassion as to what Naomi and Rebekah were experiencing within the dying landscape. It is interesting to note that Naomi was in the curative system when she was on the dying journey and one is left to ponder if the curative landscape finds it difficult to accommodate the dying landscape associated with the cancer journey. As Harris (2004) comments few oncologists are trained in palliative care with most learning by trial and error or from a role model. This lack of
understanding would no doubt also be associated with other health care professionals. This has also been confirmed in the literature in which dying in patients and their carers experienced dying in the curative system as negative with a feeling of alienation, depression and powerlessness, with the invasive technology for some causing post traumatic stress (McGrath, 2001b, 2002a). McGrath (2002b,p 45) believed “patients and their carers are being trapped in a high-tech, curative treatment that does not acknowledge dying and does not appropriately refer to the palliative system”.

Despite the home being associated with therapeutic landscapes, (Williams, 1998) for Jenny and Kerry creating this therapeutic landscape was difficult due to lack of support and the isolation they felt as carers. It is interesting that both Jenny and Kerry believed they had no choice but to care for their AYA at home. Both found caring for the AYA at home very hard and would have appreciated some respite or additional help and care. Both of these stories speak of the isolation associated with dying and advocated a more coordinated approach to this care, which would have made the landscape of home dying easier to manage.

This is confirmed by Goomes and Higginson (2006) literature review that demonstrated provision of intensive home care as associated with home dying. This is confirmed by Brown, Davies and Martens (1991) who identified the following factors associated with a home death: a willing and able caregiver; the patient is not too ill; the home environment can be adapted to meet the patients needs; and adequate services are provided if the patient is not too ill. Although there was a paradox in that patients with limited access to health and palliative care in rural areas were more likely to die at home (Gomes & Higginson, 2006). This suggests that the perceived limited choice of place of death has an influence on dying at home, as was seen with Jenny and Kerry.

Goomes and Hissinson’s (2006) review found that lack of support within the family was also a determinant of the patient dying at home. In Jenny, Kerry and Sue’s stories there was a lack of social support and limited resources. Sue decided to care for Ben in a hospice as it was too difficult at home. Jenny and Kerry believed they had no choice but to continue the hard work at home, highlighting once again the lack of place or space for AYAs and their family members.

For Sue this response to lack of support was to transfer Ben to a hospice. Sue’s story highlights how Ben’s care appeared to have been coordinated as she and Ben were
provided with alternative choices. Sue spoke of how the hospice provided a therapeutic space and place for Ben, suggesting that therapeutic landscapes can be created in other areas of health care.

**Theme: Feeling Overwhelmed**

Watching the AYA prepare for their destination and witnessing the cancer taking over within this landscape, was occasionally made more difficult by a perceived lack of support that provides the ingredients for the development of an unauthentic place. This unauthentic place has the potential to contribute to psychological distress for the family members. This psychological distress is related to the dying landscape, which is unfamiliar and frightening to most of the family members in this story, creating anxiety and fear. Psychological distress was evidenced by the family members in this study within the theme feeling overwhelmed. For these family members, feeling overwhelmed was when the cancer journey was becoming too much for them and they were overcome with a feeling of not being able to stay on top of the situation.

*Burdened with Suffering*

For Deborah she was overwhelmed with Matthew Anthony’s pain to the extent that she had a personal battle with herself about ending his suffering:

> the last month he was sleeping a lot more because when he was awake he was in pain and they never, ever managed his pain. It was never, ever fully under control … That’s very difficult to cope with … really hard. I mean if they had’ve managed his pain I perhaps would’ve maybe coped a little bit better … towards the end I couldn’t deal with it because he was just screaming in agony and it was just, awful.

Matthew had made the comment:

> “if I was a dog they would’ve put me down months ago, and why am I suffering like this?” … and then he actually begged me to kill him … but that kept playing over and over in my head and I thought my god, what sort of a person am I, he’s begging me to end his suffering and I’m saying no. But he’s my child how can I kill him and I just had this personal battle with
myself. My god what am I going to do? … and I have to, as a mother, look after him and make him comfortable. And I didn’t want to do it because I didn’t want to be responsible for killing him … I just could not bear to see him … I actually said to the doctor about a week before he died, “I can’t take this any more, he’s in agony, can’t you give him something … put him out of his misery”. I didn’t actually say it in those words, but that’s pretty much what I was getting at.

This is similar to Shane who found the last hour of Grant’s life hard and begged the doctor to give Grant more medication:

that was hard, that last hour was hard because in the end I was just begging [the doctor] to give him more, more medication … . Because I said “he is in pain” because poor old Grant he couldn’t breathe, it’s hard not being able to breathe and he was struggling a bit with that. It was killing me to watch it so … I’d gone out into the corridor to the nurses and said we need him to go … like I wouldn’t treat a dog the way we treat some of these people.

Enduring Hard Work

Kerry says there is not a word that can describe how hard it was trying to make a life when Alinta was dying and in the end she dies:

it was disgusting that time that she was alive trying to make a life for all of us, run my family, get the others to school, do everything … washing up at night, making lunches, getting up, making sure the washing’s done, the whole lot … be Alinta’s friend when she didn’t have friends that she could interact with … I couldn’t keep up with it … it was just hard. I wasn’t getting any sleep at night … It was terrifying me … I felt scared, I didn’t want to leave her and how can you leave someone who might die, with somebody else … I don’t even think there’s a word in there just to tell how I had to care for Alinta and how it felt, physically, the whole lot of it … and then she dies.

This sense of how hard it was flowed into Josephine’s story:
this sounds really awful, but I’d had enough. I couldn’t cope with it any more, I could not cope with watching him going through what he was going through, and not being with my other kids … everything was just too hard. And my mum couldn’t cope with the kids any more and they were farmed out, [my ex-husband] was useless and it was just too much, and I just wanted him to die.

Overcome with Emotion

For Lauren the day Grant died she experienced a panic attack, which she saw as a release from just trying to survive the dying process:

I had a bit of a panic attack that day, I guess my body needed a release … I don’t even know what happened … I just left and I went and collapsed outside the nurses station. I was so hot just burning up … I guess I was hyperventilating or something, I just couldn’t breathe and I was crying, crying it was horrible … it wasn’t like anything [the panic attack] … everything was just sort of blurry and hazy … I think that really it was just made by me needing to release that stress … It wasn’t real easy … I guess we were just surviving.

REFLECTIONS ON FEELING OVERWHELMED

The stories in the previous themes relate to the family members witnessing the dying trajectory and providing the care and advocacy to their loved one. It is not surprising that many of the family members felt overwhelmed by the dying process. For some they were overwhelmed by the AYA’s suffering to the extent that they wished they could end it, whilst for others it was being overwhelmed with the hard work in which the final outcome was the AYA’s death. For others this witnessing suffering and enduring hard work resulted in the family member being overcome with emotion.

Deborah was so overwhelmed with Matthew Anthony’s pain, she was forced into the overwhelming dilemma of wanting to end his suffering. Being confronted with this dilemma highlights the huge responsibility that the family members in this study were experiencing. The fact that Deborah felt so overwhelmed with Matthew Anthony’s
suffering suggests that he was not being managed from a palliative care model of holistic care. Witnessing the suffering was so overwhelming that she asked the doctor to stop it. Shane found himself in a similar situation with Grant’s suffering. Both these stories speak of the difficulty of watching your child suffer, and rather than witness this suffering, requesting help to alleviate that suffering to the extent that a hastened death may be seen as an alternative option to the suffering.

It is interesting that Matthew Anthony was being cared for at home by the GP with probably limited palliative care experience. On the other hand Grant was being cared for in a curative hospital system that focuses on treatment. This suggests that neither system of care, at this particular point in time, had the capacity to provide a landscape that was therapeutic through the dying trajectory. Associated with witnessing this suffering was the hard work associated with caring for their dying loved one, as demonstrated in subtheme enduring hard work.

All the stories in this theme demonstrate a dilemma for the family members caring for the AYA who is dying; they are aware that the AYA is going to die and there is no question that they won’t be there for them to care for them, but watching the suffering is almost unbearable. This, accompanied with the hard work of caring for someone who is dying resulted in a wish for their and the AYA’s suffering to end and for them being able to have some reprieve. Being overwhelmed with the suffering and the hard work associated with caring for someone who is dying, for some, resulted in the family member being overcome with emotion.

Lauren felt she was just surviving and the end result was a panic attack. This was a direct response of knowing and waiting for Grant to die.

All these stories in this theme are testament to the commitment and dedication that the family members have to their AYA family member. Despite the anxiety involved, the family members worked tirelessly to alleviate the AYA’s suffering. This is associated with knowing that at the end witnessing the suffering and enduring the hard work the final destination is death.

**Theme:** **Witnessing Heroism**
Despite the suffering associated with the dying landscape the AYAs managed to provide some respite from the dying landscape with their continued ability to remain positive and protect others around them. This is seen in the theme witnessing heroism. Witnessing heroism is a continuation of the theme, living the quest, which was first identified in the Exploration stage of this study. The heroism during the Destination stage is in relation to how the AYA managed the reality of dying with strength of character and resilience. Some of the ways in which the AYA managed were: accepting reality, taking control, protecting others, being grateful, and enjoying ordinary behaviours.

Accepting Reality

Cheryl’s explanation of Paul Malcolm accepting reality was in relation to Paul Malcolm being prepared for where he was going:

Paul was prepared for that all the way through, because he had been so strong … if he’d had any doubts or whatever he didn’t express them to me … So he was secure in where he was going and what he was doing, he was far stronger than me in that respect.

Susie also accepted the reality of her death, which was hard for Tania when Susie read her eulogy over the phone:

one of the hardest things for me … was when she was back home and she’d written her eulogy and she read her eulogy out to me over the phone … she’d obviously accepted [that she is going to die] … that sort of made it more final … more definite … that was one of the hardest things … hearing her read it, and she read it as if she was reading a book to you, over the phone.

Taking Control

Arlene witnessed Mathew James taking control of his dying when he made the decision for his chest tube to come out after he had said his goodbyes:
he made the decision that he would stay in hospital, keep the chest tube in, say his goodbyes and then we would take the tube out and he would be gone within 3 or 4 hours … his lungs would just fill with fluid and the oxygen wouldn’t be able to get in.

Taking control was not just confined to the AYA controlling how they died. For Deborah taking control was how Matthew Anthony planned his own funeral, which made it easier for her after he passed away:

he actually planned his own funeral … picked his own casket, told me what he was going to wear, chose his own songs … He chose the funeral director … Met with them, they brought a photo album of coffins and caskets and he said, “I want that one” … He even chose the flowers that he wanted on his casket … we actually sat down and figured out the wording on the plaque, together … it actually was a good thing. I think it was good for him but it was also good that after he passed away I didn’t have to make those decisions because they were already made. … I knew because it’s what he wanted and so that to me, is just amazing. I think that would be really difficult to plan your own funeral.

Denise witnessed Brenton James taking control by attempting to maintain his independence in front of his mates when he returned by plane to hospital when he was dying:

but they all came out to the airport and … Brenton was at the stage where he could barely put one foot in front of the other, but he would not let the ambulance guys help him up the 6 to 8 stairs up into the plane. It took him … lots of minutes to get up those stairs to lift his body, and he stood at the top of the stairs and he waved to his mates and they all waved back … very sad.

**Being Grateful**

The heroism of being grateful is how the AYA, despite dying and suffering, was still able to feel grateful for the care they were given.
This is reflected in Brenton Duncan’s story when Jenny recalled the Professor speaking of how Brenton Duncan thanked him for the care he had given when he was told of the metastasis:

The Professor his doctor, said “when he told him about his metastasis and that you’re dying,” he said “most teenagers would hit the pillow and say f this, f that, why me, it’s not fair but Brenton just shook his hand and said thank you Professor for giving me all the love and care that you gave me.” And [the] Professor had tears in his eyes and he went out to the nurse’s station and he just broke down and said “that child is a true gentleman” he said.

This being grateful carried on right up to the end stage of dying. Lauren remembers Grant saying thank you to the nurse on the day he died:

the nurse was giving him some morphine and he looked at her and he said thank you for everything.

Denise tells a similar story when Brenton James thanked the staff the night before he died, when they were trying to drain fluid from his stomach and couldn’t find where all the fluid was coming from:

the night before he’d been that swollen up … that they were inserting this huge needle into his stomach trying to find where all the fluid was and get it off and they couldn’t find it and I’m holding his hand and the doctor’s saying, “I’m sorry Brenton,” and he’s saying, “that’s all right, thank you, thank you for trying.” He was just the whole time, just the most wonderful patient you know.

**Protecting Others**

For some of the family members the heroism was in the way the AYA cared for those they loved and tried to protect them. In Brenton Duncan’s story Jenny realised he was
making life easier for others. She spoke of one incident where he was concerned about his girlfriend:

he made his death easy for me because it was never poor him, he always gave out to everybody else and he’d say “how are you?” … One night when his girlfriend was there and it was two or three in the morning he said “Chris you're not still here, oh you poor thing you will be so tired in the morning” and she said “but Brenton you’re dying I won't ever have this time with you again.” He said “oh but Chris I worry about you,” he was just so giving.

Lauren remembers Grant being her support even though he was dying:

I was pretty needy a lot of the time though Grant probably comforted me he was my strength … he was my support but he was the one dying … [he supported me] just by hugging me and telling me I’m doing the right thing … listening to me and letting me cry, telling me that it is okay for me to cry … So, I think he liked being able to take care of me … His arms were so skinny but he could still give me a hug. You could feel the heart.

This protecting others is seen with Ben where Sue believed his lack of complaining was how she got through:

he never complained and that’s what everyone said to me, no matter how much pain he was in, no matter what he was feeling, he never complained. He never said, why me? Never, he never complained to the nurses, the doctors, he never wallowed in self pity, and that’s I think, how I got through, I kept thinking he was very strong.

Enjoying Ordinary Behaviour

Following on from this theme of heroism and despite the fact that the AYA was dying, the family and the AYA enjoyed behaviours associated with normal adolescent development.
For Irene enjoying normal behaviour involved her being amused when Thomas had a few bourbon and cokes:

he got himself dressed and out he came with his friends and he sat there and he had a couple of bourbons and coke, which he’d never done before and he was so funny. He was so funny … to watch him with a few drinks inside him, we thought well there was nothing else was there, let him have a drink.

Cameron experienced normal behaviour by going to schoolies (end of year celebrations for school leavers usually at a holiday destination) with Kristie a month before she died and he felt it was a really good week, almost like a goodbye:

and so we got her to schoolies in 2000. It was a month after that that she passed away. I went up there with her because she said she knew that she couldn’t walk fast enough for the other guys so she thought just come up and to be with her, to come up and have fun with her. We went up [the coast] and we had a great week together and stuff like that, and with her friends also. Her friends were very supportive, her friends are also beautiful people so it was a really good week and it was almost like a goodbye.

For Val enjoying ordinary behaviours involved Susie making sure she could play bowls and keeping things as normal as possible:

all over the place, playing bowls and had a blood transfusion the day before so she was pretty much fit … She took up lawn bowls before she was diagnosed with the cancer, so being able to get back and play lawn bowls again before she died really meant a lot to her … very normal. I asked her to peel the spuds, and she said, “Mum, you know I can’t, I’m dying” … but everything was kept as normal as possible.

This ordinary behaviour was experienced in the hospital (hospice) when Sue spoke of how the staff thought it was fantastic that there was laughter in the hospice when Ben’s friends came to visit:

and it’s a lot to ask any 17 or 18 year old … to go and see a mate who may not live till the end of the week … but they did. They’d buy him presents, or chocolates or … they’d just come and sit quiet sometimes. A couple of them
were noisy but it didn’t matter and … the staff at the hospital, they thought it was fantastic. I said to them one day … I apologise for the noise, and they said, it’s the best thing, the best thing that could happen in a place like this is laughter.

**Reflection on Witnessing Heroism**

For the family members in this study the hard work associated with the dying journey was made easier by the AYA’s heroism. Zelcer et al (2010) noted witnessing this resilience provides parents with the strength to continue the cancer journey through the admiration they felt for the young person. Armstrong-Coster (2004) in her study on living and dying of cancer concluded that the family members encountered many of the challenges faced by the traditional hero. In Joseph Campbell’s (1949) hero’s journey stages seven and eight, the hero comes to a dangerous place, which is often underground, where the object of the quest is hidden and the hero must endure the supreme ordeal. This supreme ordeal is confronting death or facing his or her biggest fear. In the hero’s journey the hero appears to die and be born again and returns with a reward. Unfortunately, in this meta-narrative the reward is the actual death and there is no return with the boon.

Armstrong-Coster (2004, p. 178) with the family members in her study, observed the heroes lived what remained of their life with “consistency, courage and self sacrifice in the face of pain and adversity”. This theme of witnessing heroism is a reflection of this and a continuation of the theme living the quest discussed in the Exploration stage. The theme demonstrates how the AYA negotiated the dying landscape with courage, wisdom and grace. Some of the ways they achieved this was through accepting reality, taking control, being grateful, protecting others, and enjoying ordinary behaviours.

The heroism was initially seen, with the AYA accepting the reality that they were going to die. Paul Vincent’s heroism was his conviction that he knew where he was going. This is also demonstrated with Susie who left a lasting legacy behind by writing her own eulogy.

This accepting reality flowed through to the AYA taking charge of the dying process or relieving the family members of the burden of organising their own funeral. Therefore
Despite living the chaos narrative, the family members observed the AYA not submitting to the powerlessness of dying and seeking ways to still maintain some control over their world.

This is seen in the courage of Mathew James when he took control of his dying. Brenton James demonstrated taking control by displaying independence and courage when dying. Courage was demonstrated to his friends in showing that he still had some semblance of independence when he slowly negotiated the airplane steps and waving goodbye on his dying journey back to the hospital for his final destination.

Taking control was not just confined to the AYA taking control of their dying and demonstrating their independence, for some it was actually organising their own funeral. This ability to take control reflects the AYA wanting to maintain some form of self and identity, with the ability to make autonomous decisions as important right up to and beyond the final destination. This is despite the fact that they had been subsumed by the chaos narrative of powerlessness and lack of control. The family members sought to live the quest narrative by taking on the challenges of the heroes quest, whenever the opportunity arose within the dying landscape.

Despite the suffering that accompanied the AYA in the dying landscape, the stories told of the AYAs being gracious for the care they received. One can reflect that being grateful is also a way to maintain some control and to demonstrate a sense of self. This is demonstrated in Jenny’s story of Brenton Duncan who, by shaking the Professor’s hand and thanking him for all the love and care he had been given, was able to demonstrate he was still an individual with a sense of self and autonomy. An individual, who, was not totally consumed with the chaos narrative with some control of the dying journey. Being grateful did not stop throughout the dying journey with Grant and Brenton James thanking health care professionals when death was imminent. All these stories demonstrate the AYA, despite being overwhelmed with the physical reality that they were dying, still managed to convey their identity and sense of self. Instead of giving into the physical pain and discomfort they let people know they were appreciative, human and that they still had the sense of self to be able to appreciate this.

Being grateful and thinking of others was also seen in the way the AYA cared for those they loved and tried to protect. This is reflected in the way Brenton Duncan, Ben and
Grant provided the strength for those they loved with their unselfish giving of themselves.

The last two subthemes of being grateful and protecting others reflect what has been identified by Armstrong-Coster (2004) as emotional labour, attempting to protect others from their pain and suffering. She identifies heroism within this context as involving emotional expression and sacrifice. The AYAs demonstrated this heroism by deflecting concern for them onto the healthcare providers by thanking them for all the care they had given. This was also demonstrated when they thought of those closest to them when they were experiencing the pain and suffering associated with dying. As Lauren said, she believed Grant liked caring for her and both Jenny and Lauren believed the way Brenton Duncan and Grant protected others made the journey easier for them.

As with the subtheme ‘taking control,’ the AYAs in this study attempted to live outside the chaos narrative by engaging in normal behaviours, even when they were physically deteriorating and becoming more dependent on those around them. This was witnessed by Irene when she watched Thomas enjoy a few bourbons and coke. For Kristie it was being able to go to Schoolies a month before she died. Val spoke of how Susie went back to lawn bowls which Val felt was very normal. Seeking to enjoy ordinary behaviour did not just occur when the AYA was not in hospital. Sue recalls how Ben was able to engage in normal behaviour when his friends would come and visit him in hospital. She remembers the staff at the hospice thought laughter was the best thing that could happen in a place like this.

Normalcy was identified as a need in the literature review of this study, in particular during treatment (Decker, et al., 2007; 2004; Evan & Zeltzer, 2006; Grinyer, 2002a, 2007a; Miedema, et al., 2007; Patterson, et al., 2008a). This study identifies that this seeking to be normal is still a need even when death is imminent and the AYA is deteriorating physically. This is supported by Epstein, Orr and Stevens (2004) who recognised two types of enduring on the cancer journey, one of which is enduring to die. This enduring was accompanied by a struggle for normalcy which was difficult because the suffering was always present.

This normalcy is observed in Armstrong-Coster’s (2004) study in which no matter how restricted their behaviours, the family members made the most of what they could do especially appreciating their ability to continue engaging with their social bonds.
The previous themes all speak of the reality of the AYA’s death with both the family members and the AYA being aware that they had entered a different landscape in which the final destination is death. Whilst being aware of this and witnessing the AYAs’ deteriorating condition, fourteen of the family members still spoke of hope and the possibility that things may change.

Thinking About the Future

Paul Malcolm maintained hope by trying to get on with life and thinking about the future:

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\text{we were trying to go on with life, he was trying to do his Year 12. He was very much thinking into the future. He was saying, you know, he originally wanted to be a teacher and now he was saying he wanted to do physiotherapy because of the physiotherapy he’d had in hospital and he could see that was an interesting thing to do working with kids, so he was very much thinking into the future.}
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Having Faith

For Cheryl the hope was maintained by having faith in God. She talked about how, all the way through treatment, she had her feet in two camps: the reality of what God could do, and the reality of the medical diagnosis.

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\text{So there was the understanding that God is God. God is a God of healing so yes, and we knew people that had been healed … so it was to stand with one foot on either side of both realities. You know the reality of what God can do and the understanding that this is a medical diagnosis and this is serious stuff … right the way through we’d always ask him, “Paul what do you want?” His answer was always, “to be healed and to glorify God.”}
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Alan’s faith in God also gave him hope and he remembers clearly hearing the words ‘I will not fail you’ in his head and thinking Naomi was not going to die:
But as I walked out of that hospital I was in tears, and I heard these words clearly in my head, I will not fail you … I was hanging onto [to that] all of that time … I might’ve had my head in the sand. I don’t know, but I never really thought that she was going to die, even though I know she’d been told she was terminal.

**Not Giving Up**

For others maintaining hope was seen in the way the AYA never gave up hope and kept trying to believe that the treatment would make a difference. For example Deborah hoped that Matthew Anthony’s will to live would just shine through:

> I sort of always had this hope in the back of my mind that if it did come back and he had to have chemo … that will to live would just shine through, and it did … he said “well, when do I start chemo. When can I start working on this?” … they said well, tomorrow and he was happy … and … he fought it, even though it really wasn’t any point. He still kept fighting.

Sue experienced this not giving up hope through Ben continuing to fight and never losing hope:

> outwardly Ben never lost hope, until probably the end, but he never, never lost hope and he fought and fought … I remember him [the specialist] saying, “he may … be able to keep it under control for a year or so,” and that’s what I was hanging onto … for dear life because I didn’t want to accept any other, anything else, I just didn’t.

This is similar to Grant’s story where Lauren said as a family they never gave up hope looking at other options or maybe a clinical trial:

> I don’t know, it is hard. I think we didn’t really want to accept it. We hadn’t given up hope, and Grant said, “well if they can give me two years then who knows what will happen in two years … there maybe new clinical trials or there may be a breakthrough” … we looked at the other options so we hadn’t given up hope.

**Denying Reality**
Fulvia maintained her hope by believing that Jadye was not going to die and feeling guilty for accepting things for dying children:

the whole time … people like Make a Wish Foundation [were] giving her things, I used to think that’s really selfish of us to take stuff like that, give it to someone that’s dying … give it to a child that’s dying … I don’t think it’s fair … when she’s not dying … they should really give it to someone that’s dying, because Jadye wasn’t going to die.

This is similar to Irene who expressed concern that the Make a Wish Foundation was for dying children and she believed Thomas would not die:

and we always thought the Make a Wish Foundation was for somebody who was going to die … I didn’t realise he was going to die … right up until the end I didn’t realise, I probably did, but I, probably pushed it to the back of my mind.

Cameron maintained hope by saying he was in denial until Kristie passed away:

once again it didn’t hit me until she passed away. I was still in denial up until she passed away … I was still going about my business doing my school thing, just thinking that no worries chemotherapy and medications will take care of it don’t worry about it, it’s all good. I wasn’t understanding … It was worse than I was thinking it was going to be.

**REFLECTION ON MAINTAINING HOPE**

Throughout the dying journey many of the family members managed the dying landscape by maintaining some form of hope. In Joseph Campbell’s (1949) hero’s journey the ordeal is the phase where the hero appears to die and is born again. It is the major source of magic in the hero myth. The family members’ believed in the magic of the hero myth and this made it possible for them to maintain some form of hope that the hero will win over death. This hope is considered to be important in the dying journey as a form of coping (Zelcer, et al., 2010),. Thompson and Wainwright (2003, p 111) have suggested that “[h]ope is seen as critical to the psychosocial well being of patients
and families … it is about creating the possibility of something better in the future … [h]ope is about possibility – not probability” Hope was seen in the following subthemes in this study; thinking about the future; having some form of faith; or denying the reality of the journey.

Cheryl remembers Paul Malcolm, despite the fact that the cancer had spread was getting on with life and thinking about the future rather than allowing despair to take over. This future direction is a continuation of the previous theme witnessing heroism, where the AYA whenever able maintains as normal a life as possible.

For Paul Malcolm and Cheryl, thinking about the future was strengthened by their faith in God. This faith was also demonstrated in Alan’s story. This faith protected Paul Malcolm, Cheryl and Alan from the reality of the despair that death was the probable outcome. This belief in God, and its importance in making the dying journey tolerable, was evidenced in Grinyer’s (2002a) study in which faith in God assisted both the parents and the young person dying of cancer in accepting the unexplainable as being part of God’s plan.

In other stories hope was maintained by the AYAs’ belief in themselves and a sense that maybe in time there would be possibilities. Deborah talks of how when the cancer came back Matthew Anthony’s will to live shone through and he kept on fighting. This is similar to Sue who remembers Ben never lost hope and kept fighting the cancer and Sue’s hope they could keep the cancer under control for a year or so. Having more time was also spoken of in Lauren’s story, where hope was maintained by Grant believing if they could give him two years then there may be new developments in the medical field.

This maintaining hope by not wanting to accept that the AYA was going to die, as told by Lauren, flows into the next theme where hope was maintained by not accepting reality and the defense mechanism of denial.

All these stories suggest that hope is a coping strategy that allows the person to somehow deal with the reality of the imminent death of the AYA. Hope in this context could be explained as a form of denial. The ability to live with hope and despair has been described as not mutually exclusive, with hope being explained as being on a continuum ranging from despair (no hope) to denial in which people find themselves according to their changing situation or who they are (Victoria Hospice Society, et al.,
2003). The literature review also established that parents have the ability to hold on to two dichotomous beliefs, the reality of the dying trajectory and the hope of a miracle (McGrath, 2002b; Monterosso & Kristjanson, 2008). So, although the family members in this study clung to a belief in a miracle, they were all aware that the reality was death but this hope made it possible for them to deal with the inevitable.

**Theme: Saying Goodbye**

*When is it time how will I know, when the vessel has nowhere to go or is a keeper not in need?*

Anthony Barling (2002)

The acceptance of the inevitable is witnessed in the next theme ‘saying goodbye.’ The family members are aware that the AYA’s next part of the dying landscape is negotiated by the AYA with support and love as they reach their final destination. Saying goodbye for some was spoken of in the way they communicated with each other (acknowledging feelings) and part of saying goodbye was wanting to know how much longer the dying would take (how much longer). For others, saying goodbye was the family members giving the AYA permission to go (it’s OK to go).

**Acknowledging Feelings**

For some, wanting to say goodbye was associated with taking the opportunity to let others know how much they cared for each other. For example Cameron remembers Kristie saying “*I really love you*” about two weeks before she died and he knew she wasn’t going to make it:

*She said ‘oh look Cameron I really love you’ … that was an indication … it was if she knew that I knew that this wasn’t going to last any longer … she*
was letting me know she loves me and she just wanted me to know because this could be the last chance before she had to go on oxygen just to breathe.

Deborah witnessed this when watching Brenton James and a friend and knowing they loved each other but being teenage boys not wanting to show it:

I watched his friend coming down backwards, holding him, because he found it very difficult to move ... and Brenton holding onto his shoulders, and it was the most emotional thing because you could see that they loved each other and how this kid ... didn’t want his mate to die, but you know, you could see all that emotion.

This is different to Josephine who wanted so much to be able to express herself to Christopher, but he didn’t like being touched.

Christopher didn’t like being touched so I couldn’t sit there stroking his head or holding his hand, much as I would’ve like to. What I really would’ve liked to do was get on the bed with him cradled in my arms but that was not possible.

**How Much Longer**

In five of the stories the subtheme of how much longer was spoken about. This subtheme is associated with wanting to know how much longer the AYA had to live.

For Irene, knowing when Thomas was going was important because she didn’t want to miss it:

the other grandma was outside crying, and I said “this is it is it, is he gone? “Have I missed him,” and they said “no, no he’s not gone but it looks as if he’s going.”

This is different to Lauren who remembered thinking everything would be fine after Grant made it through the night and not wanting to accept that he was going to die:

But the day he died I didn’t believe it was happening because they had told us so many times he is not going to make it through the weekend, he’s not going to make it through the night, you know, say your goodbyes, don’t
leave the hospital and he would always pull through so the day he died I didn’t want to accept it ... it wasn’t until the afternoon shift change, at 2.30 whatever, and Ian came on, he was a really great nurse, and he said it will be within an hour and it just hit ... how Grant had been most of the day. It is like this is really happening and I couldn’t not want it to happen.

This is different for Deborah where it was Matthew Anthony who wanted to know how much longer and expressed relief that it would be soon:

he opened his eyes and he said, “what are you doing Mum.” I said “it’s all right Matt, I’m just giving you some more morphine for the pain, you go back to sleep.” And he said, “I’m very close, I’m going to die soon aren’t I?” And I said, “yes I think so,” and he goes, “good,” and that was it. That was the last thing he ever said and ... I just nearly fell to the floor when he said that.

Jenny asked the District Nurse if he would die that day and she didn’t know:

The District Nurses were coming every 4 hours even in the night and he started getting the death rattle that morning and I said to them “is that the death rattles?” and they said “with Brenton he could go on for another week the way he is because his heart’s so strong, even though he’s sick he could go on for another week” and I said “I thought may be today because he’s got the death rattle” and they said “no ” ... but we didn’t know that Brenton would die that day.

It’s OK To Go

For some of the family members in this study it was important for them to give permission for the AYA die.

Lauren remembers giving Grant permission to go before he died and wanting him to go because he was suffering:

the nurses said it could go on like this for days. So at that point I was thinking it would be better that he died ... I don’t want him to be living he
wasn't living he was existing and he was suffering … I said to him we’re not leaving, when you are ready to go I will be right here with you.

In Arlene’s story she felt she had to give Mathew James to God:

I told Matthew he could go, I gave him permission, out loud, and I still went through this emotional … don’t take another breath, please don’t take another breath … Time is stretching … I had hold of Mathew’s hand … and I was tired too. I just sort of half lifted his hand and put my head down … on the back of his hand, and in my head I said, “dear God, he’s not mine anymore he’s yours,” and Mathew went, haah huh [deep breath in, then out], and … God was waiting for me to say, he’s yours not mine.

**REFLECTION ON SAYING GOODBYE**

Despite trying to maintain hope, with the cancer taking over the AYA was going physically downhill, there came a time within the dying journey where the inevitability of death could not be avoided. Once the family members were accepting of the fact that the AYA did not have long to live they managed to create opportunities in which to say goodbye. This place in the dying landscape where the realisation that death is imminent is an important part of the Destination stage - that the final stage of the cancer journey is about to occur. This landscape requires a place where it is possible for the family members and the AYA to say their goodbyes with sensitivity and love. This was manifested in various ways such as not talking about dying but knowing through the unspoken that the AYA was saying goodbye. Saying goodbye was also expressed in the family members’ stories as wanting to know how much longer the AYA had to live. This wanting to know how much longer, for some of the family members, resulted in them giving the AYA permission to go.

For some this saying goodbye was with verbal and non verbal expressions of love as demonstrated in Cameron and Deborah’s stories. This emotional labour, or inability to express in words what each other was feeling, has been discussed earlier in the theme witnessing heroism. In this the AYA attempts to protect others from their pain and suffering through emotional expression and sacrifice. Although expressing the
unspoken was not always possible, as with Josephine who found it difficult that she could not express her feelings to Christopher through a mother’s touch.

Accepting this reality existed at a temporal level where it was important that the family members knew how much longer the AYA had to live. This knowing provided the final acceptance that there was no hope and the AYA was about to encounter their final destination. The family members’, wanting to know how much longer dovetails into the next subtheme where the waiting for the AYA to die is tempered with giving them permission to go.

This could be interpreted as the final goodbye. The stories speak of watching the suffering and knowing that it is time to allow the suffering to end and allow the person to enter the dying transition in peace.

**THEME: RECALLING THE MOMENT**

The final destination of the dying journey is the death of the AYA. The death generated two themes recalling the moment and extending the living connection. The moment of death was preceded by the family member watching and waiting for that moment to occur. For most it involved watching the AYA’s breathing change and waiting for the last breath. All seventeen family members who were present at the moment of death described this moment in detail. The stories reveal this to be an important part of the dying journey. For those who, for whatever reason, missed the moment felt as though they had been deprived of a seminal moment. Many of the family members, after the moment of death, felt a sense of relief that the suffering was over. After the moment of death family members wanted to extend the living connection with the loved one by staying connected with the body. This was done by staying with the body, caring for the body and viewing the body after the death.

**Waiting and Watching**

Paul Vincent’s sister, Cathie, remembers the experience as being terrible when he died, it was painful to watch:

Paul had this huge haemorrhage, had a fit … that would have been a lovely way to say goodbye but they didn’t they came in … and they raced him
down gave him Valium and resuscitated him … and he lived for another six hours, leaking from every orifice and I thought well why did you do that to him? Why did you resuscitate him? … that probably is the worst memory I have … the way he died. I’ll never forget the look on Mum’s face sitting there watching him and that was painful, because every breath he took, Mum took.

For Lauren the waiting and watching was not associated with painful memories, just waiting for the last breath and crying:

it was … kind of morbid because each breath was so far apart and so slight and we weren’t sure when he stopped … And it was like oh no I think that was a breath and he took a few more breaths and that was it … and then he kind of took this little gasp and then we were like waiting and waiting and waiting and another one didn’t come. I just started crying.

This waiting and watching was also seen with Pam when she noticed Tamina’s breathing had changed and how she would have liked to share the experience with others:

then she just went to sleep and it was a few hours later … her breathing changed … but I just sat on the lounge and watched her breathing and I thought … afterwards of all the wonderful people, like my friends, that I would’ve wanted to share that with me.

Being Present

Being present when the AYA died facilitated the transition for the family members in this study and made the experience somehow special:

In Cheryl’s story she witnessed Paul Malcolm’s spirit leaving his body before he was physically dead. She found this experience comforting:

there came a point where his breathing became very laboured and stopped for a while, and began, and …. I knew … I saw his spirit leave his body and he continued breathing for nearly ten minutes … when I saw him leave his body it was something that I couldn’t explain to anybody else, but I saw it
happen. And it’s more … in the second after it had happened … his spirit … was around near the ceiling somewhere … Very aware of that, that this person in the bed was no longer Paul and it was no longer a person and it just continued for about ten minutes … It was very comforting to be there when it happened, because I have absolutely no doubt where my son is.

Deborah also felt a real spiritual thing when Matthew Anthony died and believed it was beautiful, although sad and hard to experience. He sat up stretched his arms in the air, focused on a spot, took his last breath and slowly laid down:

we were all sitting around him and we were all with him when he died and it was beautiful, that’s really probably the only way I can describe it, it was just a beautiful experience, sad and hard but beautiful at the same time, if that makes sense … Matthew never budged when he was dying … when he took his last breath, he sat bolt upright with his arms stretched up in the air and he was looking, he was focused. He couldn’t see, he had bleeds in his eyes, they were all black. He was looking, focused on this particular spot, so much so that we all sort of looked …, there was nothing there and then he took his last breath and just slowly laid down … Maybe the scientists could come up with a scientific explanation for it but to me that was, it was just a really spiritual thing.

The moment of death explained by Deborah as being beautiful was similar to Jenny who thought she was lucky that Brenton Duncan died in her arms:

And we said “Brenny we are just going to turn you,” and we turned him and he was groaning and I was there cuddling him and that is when he all of a sudden sat up and reached up while I was cuddling him, and then he laid back down and died in my arms and it was the best – I mean it was just lovely that he died in my arms.

**Missing the Moment**

This is different for some who were not present when the AYA died and were unable to say their final farewell.

Irene said she was sad because she never got to say goodbye:
I heard this music go on, which was like Oasis, which was Thomas’ favourite band, and then Paula screamed and I knew then that was it, he’d gone … It was quite funny actually, so he just passed away, he just went to sleep and that was it … and in I went to see him and I laid by his side and I kissed him, I was sad because he’d gone and I’d never said goodbye.

For those who weren’t present in the moment, there was a sense of disbelief. For instance to Denise it came as a shock even though she knew how critical Brenton James was:

I wasn’t there … I knew how critical he was … and I never for one minute suspected that he would go without me … I walked into the room and his eyes were open obviously and I could tell that he’d gone because the life had gone from his eyes and that was the biggest shock, and my husband he just yelled, “no, it can’t be.”

Sue says she can’t forgive herself that she was not there when Ben died, even though he had not woken up and had just gone to sleep she felt she should have been present:

I can’t forgive myself either, when we knew that it was close … and he’d died, and I said, why did this happen. I was not meant to be outside, I was meant to be here … I can’t forgive myself for not being there for him when he died, and yet I was there every minute and he did not wake up … he just went to sleep … but he was not in any pain, they were giving him morphine, but … it makes no difference to me.

This is different to Val who, although knowing that Susie could die that night, felt she had to go home. She said the experience was different to when her son Anthony Charles died because he was conscious and had been talking. Susie was unconscious when she died:

I just felt that I needed to be home, and I knew the consequences of going home. If she died I wouldn’t be with her, but the fact [was] that she was in a coma and Anthony was conscious when he died. He knew I was there, we were talking only a few minutes before he died. With Susie, she wasn’t
aware that I was there and I needed to be home with Ken … as badly as I needed to be with her at the time.

**Sensing Relief**

Deborah remembered feeling guilty after Matthew Anthony died because she felt relief that his suffering was over:

I felt guilty afterwards, a few days after he died because I actually felt relieved when he died. And I think we all did, we all felt incredibly relieved because his suffering was over … in the last month everything was all about Matthew. Nothing else mattered it was just what was best for him and we all just wanted his suffering to be over.

Cameron had a similar sense of relief when Kristie died because he thought she was free:

The aftermath of that, I hate saying this, there is no easy way to put what I felt on the day, but it was a sense of relief, I know it sounds harsh but it’s amazing how, people were surprised when I didn’t cry because I said she is free. On the passing … I mean it was just like I said, a sense of freedom for her.

**Reflection on Recalling the Moment**

All these stories stressed the importance of the vigil continuing right until the moment of death. The Victoria Hospice Society (2003) explain this transition of watching and waiting for the moment of death as from doing to being, which provides the opportunity for experiences of sharing. For most this watching and waiting was associated with wanting the dying to be over and waiting for that last breath. Cathie says Paul Vincent’s dying was probably the worst memory she has because of the medical interventions which prolonged his life and suffering. The association of death with medical intervention up until the time of death has been demonstrated to cause feelings of
alienation, depression and powerlessness, with the invasive technology, for some, causing post traumatic stress (McGrath, 2001a, 2002a).

All the stories stress the importance of family members wanting to stay with the AYA patient, right up until the moment of death, to continue the living connection with the family member. This is further reinforced in the next subtheme ‘being present’.

Most of the family members in this study who were present at the moment of death they found the experience sad but in some ways special. All family members who were there at the moment of death described this moment in detail. Many felt that there was still a connection with the AYA at the time of death and they were setting the spirit free. Cheryl saw Paul Malcolm’s spirit leave the body and Deborah interpreted Matthew Anthony’s death as a spiritual experience. These examples of a spiritual connection at the time of death, Ethier (2005) would describe as a Death Related Sensory Experience (DRSE). This experience can be spiritually transforming for both the patient and the carers. Others, did not see the death as spiritual, as with Jenny who believed Brenton Duncan’s death was a positive experience. The stories all reinforce the fact that being present and being able to witness this seminal moment was a special experience that made the death an easier transition. It is interesting that both Deborah and Jenny witnessed this seminal moment at home providing a place which has been described as “providing an integrative network of physical, spiritual and psychological factors merging together to promote the creation of a healing and/or healthy place” (Williams, 1998, p. 1198).

From Cheryl, Deborah and Jenny’s stories it is obvious that being present at the moment of death was important for them to create some sort of meaning with respect to the final destination. For those who missed this seminal moment there was a sense of regret that they were not present when the AYA made the transition to the final destination. Irene found missing this seminal moment of Thomas’s death sad although she was able to express her sadness and grief physically after the death. The expression of this sadness and grief in such a physical way was obviously facilitated by the place in which Thomas died. Thomas died at home outside of the hospital space in a landscape that facilitated the open expression of emotion or what Williams (2003) would refer to as an authentic landscape.
Understandably, once the AYA died and if they had missed the moment there was mixed emotion associated with the death. For Denise it was shock and for Sue it was guilt. Both Denise and Sue’s descriptions speak of a sense of loss that they were not present at that seminal moment. Despite not being able to predict when a person will make the transition to their final destination, from the experience of the family members in this study being present at the moment of death is important in order for the family members to complete the dying journey. There was one exception to wanting to be there when the AYA died and feeling upset about missing this seminal moment and that was Val.

The AYA and the family members in this study had all had the experience of travelling the cancer journey with the diagnosis, treatment, dying, and finally death. From this study this journey was full of pain, suffering and sacrifice. Family members, despite feeling profound loss when the AYA died, spoke of relief that the suffering was over.

**Theme: Extending the Living Connection**

After the death there was a need for the family members to stay connected with the body in order to extend the bond between the AYA and the family members. Eleven of the stories spoke of wanting to stay connected to the AYA after the moment of death. This desire was noted by such things as: staying with the body, bathing the body and viewing the body.

**Staying With the Body**

Denise spent as much time with the body as she needed but found it difficult when she had to leave the body to go home:

> we got to spend as much time as we wanted to with him … But they were very, very good with allowing us to spend our time with him … and what I found was extremely difficult, when we had to leave to drive home and he had to stay there in the morgue. I hated that. I hated the fact that he was not coming home until the next day.
This is similar to Lauren whose family had as much time as they needed as a family after Grant died:

The compassion of the nurses was wonderful, they just let us have as much time as we needed and they were there if we wanted them, they just let us do our own thing. We went back in with Grant and spent some time there … I think I had the hardest time leaving … I guess I realised it is time to go when he started not looking like himself any more I didn't want to keep seeing him like that. So I hugged him and walked out.

Caring For the Body

Irene cared for Thomas’ body by kissing him, dressing him, and asking the undertakers to look after him. She also witnessed Thomas’s young friends caring for the body as they lifted him onto the undertakers’ trolley:

we dressed him in his underpants and his shorts and his Manchester United shirt and they [the undertakers] … they came in with a trolley and I said to the undertakers … “you look after him won’t you,” I said “he’s been through enough,” and she said, “sure, we’ll look after him.” His schoolmates were there that he’d been friends with for years and they helped lift him off the bed, onto the trolley … I gave him a kiss, and he used to hate it because I wear lipstick, and every time I used to kiss him on his forehead I used to leave a lipstick mark and he used to rub his head trying to get it … Of course, I had lipstick on and I kissed him, and I said, “oh sorry Thomas, and I rubbed it off myself, and off he went.”

Deborah cared for Matthew Anthony’s body by dressing him and making him warm after he died and she said it made her feel better:

the funeral director really helped … when they took him away … he was just in his boxer shorts and the funeral director actually said to me about bringing his clothes in the next day and when I took them in, he said to me, “do you want to dress him” … I sat down and I thought about it, and I thought, I was the first person to put clothes on him and I’m damn well
going to be the last person. So I did, I dressed him and silly little things [is] I put 2 pairs of socks on his feet because he always got cold feet and I … put his blanket over him so he didn’t get cold and then I thought afterwards well that’s silly, because he’s dead and he’s not going to feel the cold. … I’m glad I did it, even though technically I guess he couldn’t feel the cold, it made me feel better that I had rugged him up and he was nice and warm.

This is different to Alan who went numb with the thought of washing Naomi after she died:

after she actually passed away my sister-in-law said, “come on we’ll wash her” and I went numb … then my comment was, “I kept her dignity in life and I’m keeping her dignity in death” and … there was no way I could do it.

Viewing the Body

For Arlene it was recommended that she view the body so her last memory was not of the struggle that Mathew James had endured:

When Mathew died, in my mind I had a picture … that painting called The Scream, that was what I saw it as, while he was struggling for breath, that half open mouthed struggle … and he said to me, “that would be your last memory, but if you go and you see him in the funeral parlour you will see him peaceful and that will be your last memory” … and then I went back in. I stroked him all over, I talked to him.

This is similar to Sue whose family viewed Ben after he died so they could say goodbye and she just wanted to pick him up:

So we went to see him that afternoon and I said, “you have to see Ben, you have to see him again” … he looked very peaceful and very calm, and it was very, very hard … I just wanted to pick him up.

Reflection on Extending the Living Connection
The moment of death did not limit the family members’ connection with the AYA in this study. There was reference to being with body after death to continue the bonds that had been established in life. The ways that family members maintained the bonds with the AYA included staying with the body after death, bathing the body after death, and viewing the body after death.

The stories spoke of appreciating the fact that they could spend time with the body in order to say their final goodbyes. The compassion of the health care professionals, which facilitated this, was also evident in the stories. This wish to stay with the body reflects the family members’ desire to continue the living connection. Both Lauren and Denise found it difficult to leave the body even though they were aware that the AYA had died, it was the final goodbye and the realisation that the struggle was over. This wanting to maintain the living connection was also evident with the family members wishing to care for the body after death.

The stories of caring for the body after death express the poignant moment of wanting to stay engaged for as long as possible and continue the caring after death. In Thomas’ story it was not only the family member but his friends who wished to engage with the body.. Irene and Deborah’s stories describe how the moment of death is not the end of the dying journey. Caring for the body maintained the family members’ bonds with the AYA and provided them with a sense that they were still connected with the person they loved. This was different for Alan who, thought that washing Naomi was something he would not have done in life and he wanted to respect that father/daughter relationship.

As with staying with the body after death not all the family members engaged with caring for the body after the AYA had died. For others they just wanted to view the body after death to say their final goodbye. For some, like Arlene, viewing the body was important because Matthew James’ death had not been peaceful and she was left with haunting memories. Viewing the body allowed Arlene to see him at peace, which is also reflected in Sue’s story.

All these stories speak of the importance for the family members to engage with the body after death. The Victoria Hospice Society et al (2003, p 270) acknowledges that rituals at the time of death “give people an opportunity to honor the person and then acknowledge, symbolically the death and its significance.” It is described as “an attempt to bring wholeness that has been altered by a transition” (Beck & Metrick, 1990, p. 1)
and signifies a turning point by moving towards something new and unknown (Beck & Metrick, 1990) “which may provide comfort and perspective during times of pain and sorrow” (Victoria Hospice Society, et al., 2003 p 270). For the family members in this study, the connection with the body at the time of death, or soon after death, provided them with the opportunity to honour the death of their loved one and is symbolic of their final act of care giving. Because of the importance of honouring the person who has died, health care professionals should gently invite the family members to do for themselves as much as they are able (Maus-Fielders, 1995). This opportunity to be with the body and to care for the body facilitated the transition to the hard work to come of grieving. As summarised by the Victorian Hospice society et al “[d]eath brings one person’s journey through life to an end. It also ushers in the next stage of the journey for those who are left behind” (2003, p. 276).

**Discussion of the Dying Landscape: Destination Turning Point**

An overarching issue associated with the Destination stage of the cancer landscape was the management of the dying journey. De Jong and Clarke (2009) described a good death was dying where one wishes, not dying alone, having a sense of a life well lived, having a long life, having the opportunity to say goodbye and prepare for death, and a death free from pain and suffering. A bad death was associated with loss of control and independence. The AYAs attempted to maintain as much control as possible in ways such as controlling the death, determining their funeral, and in simple ways such as maintaining their identity with friends and others.

A good death is facilitated by people being involved in EOL decisions early in the dying journey. Stillion and Papadatou (2002) and Palmer and Thomas (2008) recommend that palliative care be introduced concurrently with the diagnosis. Clayton, Hancock, Butow, Tattersall and Currow (2007) in their clinical practice guidelines for communicating end-of-life issues with adults, believe health care professionals are uncomfortable discussing these end of life options. Reasons cited are “perceived lack of training, stress, no time to attend to the patient’s emotional needs, fear of upsetting the patients and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment” (Clayton, et al., 2007, p. 83). Given these reasons for not initiating end of life discussions with adult patients, issues associated with AYAs and their families would be even more complex and confounded. The family members in this
study did not appear to engage in EOL discussions and rarely was palliative care mentioned in the stories.

Of the seventeen AYAs in this study only four died at home. This is despite the fact that research demonstrates and patients believe the best place for an AYA to die is at home. (Bell, et al., 2010; Foreman, et al., 2006; Grinyer & Thomas, 2004; Hinds, et al., 2004; Palmer & Thomas, 2008; Stillion & Papadatou, 2002). Home is a place in which Williams (1998) describes as an authentic place in which the AYA and the family are psychologically rooted. Brown et al (1991) comment that home death facilitated being there, sustaining relationships, normalcy, self direction and reciprocity which are all important elements for the AYA and the AYA’s family members’ journey. In this study Irene believed that the decision for Thomas to die at home was right. Although Jenny and Kerry more or less believed there was no alternative place for their AYAs. Jenny because there was nowhere for young people who are dying, and Kerry because she had been told that it was the best place for Alinta to die. Both felt unsupported with caring for Brenton Duncan and Alinta at home and found it hard and exhausting. At the other extreme Deborah had to fight to convince the hospital to have Matthew Anthony die at home. Fulvia had promised Jadye that she would die at home but once she was admitted to hospital to control her pain Fulvia was informed that Jadye was too sick to move to either home or palliative care. For the others in this study there appeared to be no discussion as to the place of death or other EOL decisions.

This reflects what research studies have illustrated that dying in a curative system results in EOL discussion occurring too late in the dying journey for appropriate end of life decisions to occur (Bell, et al., 2010; McGrath, 2002b; Wolfe, et al., 2000). Added to this is McGrath’s (2001a, 2002a) study that reported carers in the curative system were not provided with information about alternative places to care for the patient when dying. Wittenberg-Lyles, Goldsmith & Ragan (2011) describe this as the isolated journey occurring within a curative, biomedical structure limiting opportunities to discuss end of life care. This is in contrast to the comforted journey in which palliative care is introduced on diagnosis enabling life prolonging treatment and comfort care. The comfort journey provides opportunities for open communication on advanced care planning and end of life decision making (Wittenberg-Lyles, et al., 2011).

It is not known if the AYA or the family members in this study were engaged in any EOL discussions, which suggests that this did not occur. Adding further support to this
is the fact that only one AYA died in a hospice and of the four who died at home only Irene appeared to have seen this as a choice. Jenny and Kerry felt they had no choice and Deborah had to fight for her choice for Matthew Anthony to die at home. Jenny described the care as ‘higgledy-piggledy’ with no plan or coordination. This supports the idea that palliative care be introduced early in order for patients and family members to plan their model of care (Hinds, et al., 2004; McGrath, 2002a; Palmer & Thomas, 2008; Stillion & Papadatou, 2002; Wolfe, et al., 2000), which is timely and integrated (CanTeen and Cancer Australia, 2009) and structured and coordinated (Palmer & Thomas, 2008). Research has indicated that if palliative care is introduced early, the AYA is more likely to die at home (Palmer & Thomas, 2008).

Overlying what appears to be little opportunity for the EOL decisions, is the family members’ intense commitment to sharing the dying landscape with the AYA which involves many sacrifices. This hard work and sacrifice resulted in many feeling overwhelmed with the day-to-day care of a loved one who is dying. Added to this was the experience of feeling unsupported in the delivery of care. Despite this there was no mention of counselling being provided for either the AYA or the family members. The OnTrac Practice Framework states that access to supportive care is essential for young people facing death (Palmer & Thomas, 2008). The National Service Delivery Framework mentions the profound effects on families when witnessing the cancer journey or death of a young person. The Framework recommends that service delivery should be mindful of these relationships and recommends grief and loss support is needed for AYAs and their families (CanTeen and Cancer Australia, 2009). This is supported by the OnTrac Practice Framework which recommends supportive care be available to family members and partners (Palmer & Thomas, 2008).

The final place in the cancer landscape is the end stage of dying in which the AYA becomes increasingly dependent on the care of others. Palliative Care Australia (2005) stresses the importance of loved ones being informed about what to expect, how to respond and who is available to assist them. This information should include the physical process of dying (i.e. changes in breathing patterns); psycho-education; and looking for signs of symptom relief (Palmer & Thomas, 2008). It is not evident in Deborah’s story if she had been provided with information about dying and how to manage the pain associated with Matthew Anthony’s dying. There is the possibility that
with adequate information she may not have ended with her dilemma of how to end his suffering.

It was only at the time that death was imminent that the family members were free to let the AYA go and end their suffering. It was important to say goodbye and to be there at the moment of death. After the death the family members continued their connection with the AYA with body caring rituals. The importance of this for the family members was evident in that they wished to describe in detail the moment of death and what occurred after the death. This highlights the need for health care professionals to be cognisant with the family’s needs during and after the death and to see the person as not just a body. Whilst there was a sense of relief at the moment of death, this moment augurs the transition to another stage incorporating the loved one into their life with memories and rituals.

This chapter like the previous chapter reinforces that there is no established best practice model of care for AYAs and their families. The Destination stage can be tempered with limited end of life discussions, resulting in different focuses of care and possibly avoidable suffering.

**CONCLUSION**

The meta-narrative of the cancer journey for the family members’ experience of an AYA family member dying of cancer was created from the configuration of the themes and subthemes identified in the family members’ stories. This meta-narrative resonates with Armstrong-Coster’s (2004) characteristics of the contemporary dying hero, which are to defend or protect others, increased appreciation of life and endurance of illness. The AYA patients in this study clearly demonstrated these characteristics as they managed their dying with courage and dignity and protected others from their pain and suffering.

The Destination stage of the experience of family members occurred when the AYA and the family members became aware that treatment could no longer cure the cancer and that the AYA was going to die. Once again, as with the treatment phase, the way the AYA and the family members were told was important as to how they handled this devastating information. There appeared to be limited choices as to where the AYA
could die. For some the choice was so limited that they felt they had no choice but to care for the AYA at home. This was difficult because for them there appeared to be no support to carry out this care. The family members noticed that once they were aware of the fact that the person was going to die, the care that was given was more about symptom management than controlling the cancer.

Once the family members were aware that the AYA was going to die they were required to witness the decline in the AYA as the cancer took over the body. This resulted in having to manage the debilitating symptoms, which are part of the dying journey as well as seeking to control the pain. As with the treatment phase of the cancer journey it was important for the family members to stay connected and supportive to the AYA, this involved them keeping a vigil as they watched the AYA deteriorate. This staying with the AYA provided the opportunity for the AYA and the family members to strengthen their previous bonds.

Despite the AYA entering the Destination stage of the cancer journey many felt that there was little understanding of what they were going through. This was seen with lack of care in the hospital and feeling unsupported at home. For some these resulted in them feeling overwhelmed with supporting the AYA through the dying process. For some being overwhelmed was related to having no control over the suffering of the AYA, whilst for others it was being overwhelmed by how hard it was to maintain this vigil and provide the care and support which was required.

For the family members in this study it was the courage and strength of the AYAs on the dying journey that made the journey easier for them. This was witnessed in the way the AYA accepted the reality of them dying, how they took control of the dying and how, despite being in pain and dying, they were grateful for the care they received from others. This is also evident in how they protected and supported the family members and how despite the fact that they were dying managed to engage in ordinary AYA behaviours.

It was important that the family members and the AYAs maintain some form of hope to help them travel this trajectory. This was achieved by thinking about the future, having faith that God might intervene, not giving up the cancer struggle and for some denying the reality that the death was a certainty. Finally, despite the importance of maintaining hope there came a time when the reality that the person’s death was imminent that they
needed to say goodbye. This was done in several ways by communicating the love and care that the AYA and the family members felt for each other, to wondering how much longer it would take before they said the final goodbye, through to giving the AYA permission to go.

The death of the AYA was the final moment on the cancer journey. The majority of the family members found this moment very significant and spoke in detail of that final moment. Many spoke of waiting for the final breath. It was important that they were present at the final seminal moment and many spoke of how special this moment was. Those who did miss the moment were disappointed that they were not present for that seminal moment. Because of the struggle of the cancer journey until the moment of death, many spoke of the relief they felt when the AYA died as the suffering was over.

The connection with the AYA did not terminate at the moment of death. Many sought to extend this living connection by being connected with the body after death. This was demonstrated in various ways, staying with the body for as long as possible, caring for the body by washing and dressing the body, and having the opportunity to view the body after death.

The next and final chapter provides an overview of the process and findings of this study. The chapter summarises how the stories in this study provide insights into the care of AYAs and their families, in the context of the present systems of care. These insights provide a platform for recommendations about how care can be provided in a compassionate and coordinated way for the AYAs and their families.
CHAPTER EIGHT: CONCLUSION

ENDING THE STORY

“Once you know the end of the story, every part of the story contains that end, and is only a way of reaching it.”

Leah Stewart (The Myth of You and Me)

http://www.goodreads.com/quotes/show/163688

INTRODUCTION

This chapter provides a brief overview of the research study, its purpose, the methodology chosen, the method used, insights gained from the stories, the implications of these insights, suggestions for further research in this area, the limitation of the research, visions for the future and finally reflections of the research process for myself as the researcher.

OVERVIEW OF STUDY

Research of AYAs with cancer has developed significantly over the last 20 years. Research has demonstrated that AYAs with cancer are a forgotten population, who require closer study in order to understand their unique problems (CanTeen, 2005; Ewing, 2005; Michelagnoli, et al., 2003; O’Connor, 2006; Palmer, et al., 2007). This study sought to understand the experience of family members during the cancer diagnosis, treatment, dying and death of an adolescent or young adult (AYA). My own motivation to understand the experience of these family members was related to my own isolation and lack of information when my 16 year old son Anthony, was diagnosed with and eventually died of cancer.
Further to this the literature review which was organised according to Armstrong-Coster’s (2004) stages of the cancer journey; Departure, Exploration, Anticipation and Destination revealed, limited studies for AYAs and their families. Given the limited research in this area this study seeks to provide further insights into this cancer experience to increase the understanding and knowledge for AYAs, their families and health care professionals.

To provide a greater understanding of what this experience was like for family members requires a methodology that resonates with the aims and objectives of this research and the researcher. Narrative inquiry was chosen as the most appropriate methodology for the following reasons. First, because narrative inquiry lends itself to the teller and the listener sharing common deep structures or common meaning, of an event (Bruner, 1987). This deep structure or common meaning relies on the knowledge the researcher brings to the story and is increased by “an empathetic understanding of the ‘other’,” upon having shared the same experience as the ‘other’ (Franzosi, 1998, p. 547). Second, the telling of stories of suffering provides the opportunity for people to make sense of their suffering (Frank, 1997). Third, the study is attempting to reconstruct the experience of family members, to learn more about the experience of family members whose AYA relative lived with and died of cancer.

**EVIDENCE OF AIMS AND OBJECTIVES BEING MET**

**Research Aim and Objectives**

The aim of this study was to uncover through family members telling their stories their experience following the diagnosis, treatment, dying and death of an adolescent or young adult member (aged 16-25 years).

The objectives were:

1. through storytelling, to develop a deeper understanding of the experience of family members, through the trajectory of diagnosis, treatment, dying and death of an AYA with cancer;
2. identify issues which influence the experience of family members with an AYA living and dying of cancer.
The research aims and objectives were fulfilled in the following way:

Narrative inquiry provided the space for the family members to speak openly about their experiences of an AYA family member living with and dying from cancer. The stories from this study increased the understanding of the experience of family members following the diagnosis, treatment, dying and death of an adolescent or young adult member (aged 16-25 years).

The stories spoke of the experience for the family members whilst negotiating the cancer landscape through the stages of the cancer journey. The core stories, themes and subthemes identified specific issues that were particular to the AYA and the family members being cared for within our present system of health care. These included the hospital landscape, isolation and lack of understanding from health care professionals with communication being of major concern. Further to this the stories speak of ad hoc and uncoordinated care. In addition there appeared to be little discussion on end of life decision making, with many of the family members feeling unsupported and exhausted throughout the dying trajectory.

**Method**

The family members in this study were a purposeful sample of family members who had experienced the death of an AYA (aged 12 to 25) to cancer. The number of people interviewed was 26 with 18 individual interviews and the remaining interviews with different combinations of family members. The interviews were open-ended. All interviews were recorded on an iPod and professionally transcribed.

The study utilised narrative analytic methods to create a configured plot or core stories and a configured meta-narrative from which commonalities and differences within the core stories were identified. Guidance was obtained from the following narrative theorists; Mishler (1986), Riessman (1993, 2004a), Polkinghorne (1995), Lieblich, Tulval & Zilber (1998), Emden (1998a,b), Kleinman (1988), Frank (1997), Sakalys (2000, 2003) and Hyden (1997) to create these narratives. In addition Taylor’s (2006) computer-assisted method and the qualitative research software program NVivo8 provided a framework to configure and organise the stories. Ethics approval was obtained through the Southern Cross University Human Research Ethics Committee.
INSIGHTS

The creation of the core stories and the thematic analysis and interpretations of the family members’ stories to create a meta-narrative, demonstrated that this is an area that requires more research and understanding. The lack of understanding associated with the AYA’s and family member’s experience can be explored through the concept of the therapeutic landscape. This involves perspectives from health geographies which are associated with place and space of care and explore physical, individual, social and cultural factors that create healing landscapes (Gesler, 1992). The stories in this study provide insight into the health geographies of the cancer landscape for the AYAs and their families from the time of Departure until Destination. The landscape was often far from therapeutic with limited therapeutic place or space for this group of people and their families.

The stories within the cancer landscape speak of the suffering associated with cancer treatment and the dying trajectory, and the burden of care in trying to support these young people through this landscape. Throughout the journey the AYA finds it hard to engage in age appropriate behaviour and be connected with family and friends and other AYAs with cancer. All experiences occurred in a landscape where there were, at times, difficulties with communication mainly with health care professionals to family members and the AYA. The experience associated with negotiating the stages of the cancer journey, within this landscape, resulted in a sense of powerlessness as the family members witnessed the suffering and the eventual death of their loved one. Of particular note was the invisibility of the family members for whom, despite being connected and supportive of the AYA patient, there was evidence of the cancer landscape not having the place to include and support them through their journey.
Departure Stage

During the Departure stage there was initially little concern expressed by the AYA and the family member that the signs and symptoms could be cancer. This was related to the age and health of the AYAs. When the AYA did present to the health system, in some cases, there was a delay in confirming the diagnosis. Some of the diagnostic tests, particularly the biopsies, were the AYAs’ and family members’ first initiation into the cancer landscape and this was accompanied by feelings of distress and concern. Once the diagnosis was confirmed, how they were told made a difference in how well they assimilated the information about the cancer. For some the information was given in a caring and thoughtful way. Whilst for most the information was given in a matter of fact medical way and this made it difficult for the family members to assimilate the information to the extent that there was confusion, for some, as to whether the AYA had cancer or not.

Exploration Stage

During the Exploration stage the problems of communication continued. There was a lack of understanding of the information. The family members wished to have more information in order to make informed decisions, with the health care professionals determining what information to give and to whom. At times the family members were excluded from the information whilst at other times it was the AYA who was excluded from the information.

The AYAs were either treated in the paediatric or the adult cancer landscape. This resulted in the AYA being subjected to a landscape that was not conducive to healing. This was particularly evident if they were treated in the adult cancer wards. This landscape was aesthetically unpleasant with comments that it would be difficult to get better in this hospital setting. Another issue of concern in this cancer landscape was the social impact of the hospitalisation. For the parents this was mainly in response to being unable to perform familiar roles as a result of caring for the AYA with cancer.

In addition to this social impact, the reality of hospitalisation resulted in the family members and the AYA feeling lonely and isolated from family and friends. This was even more evident for those who were dislocated from their family home. Many of the
family members spoke of how health care professionals within this landscape had little empathetic understanding of the needs of AYAs and their families. Overlaying this was the waiting for care, care and treatment being dependent on the number of beds, and the availability of the health care professionals.

Given that the AYAs were admitted to cancer wards they were regularly confronted with death and dying, which was particularly evident in the adult cancer landscape where many of the patients were old and dying. For most this was their first hospital experience with many of the stories speaking of a patient dying in the bed next to them. Some of these deaths were described as horrible to watch. For the majority this was their first experience of death and dying. The current cancer landscape resulted in the AYAs and the family members being misplaced in the system. The AYAs in the paediatric cancer landscape were surrounded by young children and babies and this resulted in inappropriate younger activities and care being provided from a child’s perspective and the developmental needs of the AYA not being properly considered. This restricted the AYAs’ age appropriate behaviour because it would be considered out of place in the paediatric landscape. Also, within this landscape, many of the AYAs were misplaced because of their physical developmental stage - with some being almost adult.

On the other hand, the experience of being surrounded by old men and women in the adult landscape was sad and distressing for the AYAs and the family members. Being confined within these two landscapes resulted in distress for family members with the knowledge that there was nowhere else for the AYA to go. For those AYAs in the adult landscape, care was fragmented across different hospitals with, the AYA being the only young person on the ward, at times. As a result the AYA and the family members were isolated from other AYAs with cancer and their family members and were unable to share their experience and support each other through the journey. This fragmentation and isolation within the hospital landscape was exacerbated by health care professionals having little understanding of the unique needs of the AYAs and their family. Therefore, the reality of hospitalisation and the hospital cancer landscape would tend to confirm that there is no real space or place for these people within the current health care system.

The family members in this study all had to endure watching the pain and suffering that the AYA experienced as a result of their treatment The AYAs in this study all received
chemotherapy, radiation therapy or surgery. Some received all or two of these. This involved the AYA passively accepting the reality of treatment and coping with the consequences as best they could. Most family members described the effects as horrible and gave graphic accounts of how much the AYA suffered due to the treatment. This was mainly associated with chemotherapy and surgery.

Family members experienced feeling helpless and powerless which is associated with Frank’s (1997) chaos narrative. Trying to manage the side effects associated with treatment, and support the AYA through treatment, family members required an understanding of the side effects. Many said they were not prepared for the side effects. In addition most found witnessing the side effects of treatment exhausting. The unpredictability of when the side effects would require the AYA to be admitted to hospital was described, by one family member, as like a roller coaster ride. This again demonstrates a possible lack of communication from health care professionals with regard to management of the cancer journey.

Despite the powerlessness of having to witness the horrible side effects and the suffering associated with this, all the family members in this study sought to stay connected and supportive of the AYA during their hospitalisation and treatment. This was done in various ways. The family members spoke of how they were able to strengthen existing relationships as the AYA became more dependent on them throughout the cancer journey. For some the strengthening of the relationships opened up communication with the AYA and the family members about death and dying. Those family members who were not able to speak about death and dying, in retrospect wished they could have. The family members in this study, despite difficulties, made every effort to stay with the AYA. Some of the stories speak of the family member staying with the AYA and making the hospital experience less frightening.

Wherever possible the family members sought the opportunity to be involved with the AYA’s care. This was stressful and involved sacrifices from the family members with many of them being there 24/7. Because of the age and life stage of the AYA, many family members were unsure how much hands on care was possible because of perceived attitudes of the health care professionals. Due to involvement with the AYA’s care over time family members often became knowledgeable about the AYA’s treatment and care. For some this resulted in watchfulness to ensure that no mistakes occurred.
It is interesting that there was little reference to what helped and supported the family member during this stressful time. For some it was the social workers who informed the family members of what help and support was available to them, and for others it was cancer support organisations. On the other hand, others had to seek outside assistance for themselves and the AYA. The family observed that what helped the AYAs was the development of special relationships with health care professionals. These professionals treated the AYA in age appropriate ways and had an understanding of AYA issues and behaviours.

Despite the reality of the hospital cancer landscape and the horrible side effects of treatment and the operations, the AYAs maintained a positive attitude, which the family members said made it easier for them. This positive attitude was witnessed in the way the AYAs dealt with the losses associated with the cancer journey and their focus on the future. Whenever possible throughout the whole cancer journey they sought to engage in normal AYA behaviours and leave the cancer behind. This seeking to be normal is even more pronounced for those AYAs who were told they were in remission or cured. The consensus was to leave the cancer behind and just get on with life.

The Departure, Anticipation and Exploration stages speak of the importance of the family member staying connected and supportive of the AYA as they depart from the previous landscape and enter and explore the foreign cancer landscape. These stories related to the reality of hospitalisation and watching the inevitability of treatment. All speak of a landscape that is unauthentic, resulting in a negative sense of place. Current literature confirms that specialised care in Teenage Cancer Units has the potential to create an authentic landscape resulting in a healing sense of place (Geehan, 2003; Grinyer, 2007a, 2007b; Kelly, et al, 2004; Mulhall, et al, 2004; Wilkinson, 2003). The literature review revealed that there is no research on how to care for the families of AYAs during this journey, as most of the research was confined to families of children or younger adolescents (Bjork, et al., 2005; McGrath & Phillips, 2008a; Woodgate & Degner, 2004).
Destination Stage

For the AYAs in this study who thought they had a reprieve, the reprieve was ended when they exhibited signs and symptoms that alerted the AYA and the family members that something was wrong. For most, tests and investigations were quick to confirm the return of the cancer. Although for AYAs who had transitioned from the paediatric to the adult system there was evidence of lack of communication within these two systems, as was seen in one story that resulted in a delay in diagnosis. Once again, as with the Departure stage, the way that the family members were told of the impending death was not always satisfactory. There was no evidence of a plan or for thought given to how the family members were told and there was little support for the AYA and the family member after the pronouncement. Understandably the response for most was shock and devastation. The family members noticed that with the pronouncement of impending death the focus of care changed both in where and how the care was delivered. Where, the final destination occurred varied from hospital, hospice or home.

In some of the stories it is not evident if they were provided with alternative choices, and there was an underlying assumption that they would die in hospital, whilst for others there was a sense that there was no alternative but to die at home. Only one of the AYAs died in the hospice landscape, which was described as a caring and compassionate place. How the care was delivered also changed. There was a range of care options including, continuing with treatment but just enough to improve the quality of life, not subjecting the AYA to unnecessary tests and procedures, to deciding not to have any more treatment in order to not prolong a poor quality of life.

It became evident to the family members in this study that the AYA was dying when they noticed their health was going downhill. The family members became aware of this when they noticed the cancer had taken over other parts of the body. For others it was associated with having to deal with the symptoms associated with the cancer taking over, such as blindness and deafness, seizures and behaviours associated with neurological deterioration. For others it was the AYA being overwhelmed by severe pain, which saw the AYA beginning to deteriorate from then on.

Similar to the Exploration stage the family members sought to stay with the AYA as much as possible. However, this time it was associated with keeping a vigil and trying
to care for the AYA as their condition deteriorated. For many this involved lack of
sleep, being at the hospital 24/7 and being concerned that the AYA might die without
them being present. As with the treatment phase, keeping a vigil with the AYA
provided the opportunity to strengthen existing relationships. This involved an
understanding that the AYA was going to die and the consequent development of
intense bonds. Throughout this experience, the family members occasionally felt
unsupported which made keeping a vigil difficult. This was evident in the lack of care
and acknowledgment that the AYA was dying, by some hospital staff, and not being
enough resources to support the family members in their home. Some spoke of lack of
coordinated care, particularly if the AYA was at home. For one family member this lack
of support required the AYA to be admitted to a hospice where he was the youngest
person.

This lack of support whilst the family members maintained a vigil resulted in the family
members at time feeling overwhelmed with the burden of care. To the extent that one
story spoke of questioning whether to end the AYA’s suffering and pain. The majority
spoke of how exhausting and hard this vigil was to the extent that they just wanted the
AYA to die so the suffering was over. This hard work and witnessing the suffering
caused some of the family members to become overwhelmed by emotions.

Once again, as in the Exploration stage, despite all the suffering and all the hard work
that the family members had to endure, the journey was made easier by the courage and
strength of the AYA who, rather than engage in self-pity, displayed behaviours that
made the journey easier for the family members. The family members spoke of the
AYAs accepting the reality that they were going to die and conveying this to them with
courage. The majority the AYAs who knew they were going die took control of their
dying, their funeral, and how they managed the dying trajectory, demonstrating
independence and courage to others. This courage was also evident when the AYA
could still find the time to be grateful to those who cared for them, and thought of and
supported others as they themselves were dying. As in the Exploration stage, the AYAs
wherever possible, sought to maintain and engage in normal behaviours.

It is evident from the stories that the family members knew their family member was
going to die. Despite this it was important for many of them to hang on to some hope
that things might change. This hope was evident in the AYAs still focusing on the
future or to having faith that God would intervene. Others maintained hope by
continuing to believe that the treatment might make a difference and there might be other options before the AYA died and others sought alternative therapies. For others hope was maintained by denial and not accepting the AYA was dying.

Towards the end of the dying process, the family members spoke of the different ways they said goodbye. Some of the family members knew that the AYA was saying goodbye by the way they communicated their feelings. During this time the family members wanted to know how much longer the AYA had to live, mainly because they wanted to say goodbye and for the suffering to be over. Added to this many thought it was important to give permission for the AYA to go because it was time to let them go.

For all the family members in this study the moment of death and being connected with the body after death were an important part of the Destination stage. For some this final moment of death was associated with waiting and watching for the last breath. For most waiting for the last breath was not painful it was almost like just waiting for the end of the journey. All wanted to be present when the AYA died. For those who were present many felt lucky, some interpreting it as a beautiful spiritual experience. Those who missed the moment felt disappointed that they couldn’t say a last goodbye. For some who had missed the death there was a sense of disbelief that the AYA had died. The majority of the family members spoke of a sense of relief that the AYA’s suffering was over. It was important that after the AYA died that the family members were given the opportunity to extend the living connection with the body after death. For some this meant spending time with the body after death, others found it important to care for the body in more physical ways such as washing and dressing the body, whilst others viewed the body after death which helped say goodbye as the suffering was over.

**Implications for a Best Practice Model for AYA’s and Family Member’s Cancer Journey**

The introduction and the literature review of this study speaks of the AYAs and their families as not having a place in the health care system in which there is understanding of the unique needs of this particular age group. This study, using narrative inquiry as the methodology, uncovers through family members telling their stories, the experience of families through the four stages of the cancer journey identified by Armstrong-Coster (2004). The study expands the body of knowledge related to the unique needs of this group of people. Whilst the insights of this study cannot be generalised, the study
demonstrated that the stories told by the family members do have implications for the cancer landscapes that other AYAs and their family members journey through. From the stories it is evident that the present cancer landscape does not accommodate a therapeutic space or place for this unique group of people.

AYAs are currently cared for either in the adult or paediatric cancer landscape with specialist knowledge and understanding of either children and/or adults. The study supports the recommendations of the National Service Delivery Framework for Adolescents and Young adults with Cancer (CanTeen and Cancer Australia, 2009), the OnTrac Practice Framework for working with 15-25 year old cancer patients treated within the adult health sector (Palmer & Thomas, 2008), and the UK Palliative Care for Young People Aged 13-24 years Report (Joint Working Party on Palliative Care for Adolescents and Young Adults, 2007).

The recommendations from The National Framework and the OnTrac Framework include the AYA family and palliative care. The National Framework recommends that the family be considered at all stages of the cancer journey, although, there is no mention of how to support the family member through this journey. Added to this is no mention of when and how palliative care should be introduced to this cancer landscape. The Framework does provide a more treatment focused outlook on how to manage the psychosocial needs of the AYA and the family (CanTeen and Cancer Australia, 2009). Similarly, the On Trac Practice Framework emphasises that the practical needs of an AYA are enmeshed with the family, which are rarely addressed in the adult system of care. As such, the Report recommended that “the participation of the family in the care of the AYA patient must be negotiated and reviewed during all stages of care” (Palmer & Thomas, 2008, p. 59), in addition to support to help the family members cope (Palmer & Thomas, 2008). As with the National Framework there are no recommendations on how to implement this. The Framework highlights the difference of palliative care for AYAs in comparison to adult palliative care, with family involvement being considered significant (Palmer & Thomas, 2008). Despite these recommendations for service provision, the two reports focus mainly on the AYAs and not the family members. Further to this the Palliative Care for Young People Report provides little acknowledgement of family members.

Moreover, The National Palliative Care Strategy (2010) identified unmet needs for defined population groups, AYAs were not mentioned as a defined group. Once again
adolescents were included in the same cohort as children (Australian Government Department of Health and Ageing, 2010). This exclusion of AYAs as a defined population group further highlights the invisibility and lack of awareness of AYA issues within policy making areas.

Added to this Ferrari et al’s (2010) article, which examined international attempts to establish ideal models of care for AYA cancer patients, acknowledged an ad hoc implementation of models of care. The models of care have evolved in response to local issues, variations in funding, different medical cultures and resource issues providing a diversity of models of care. This suggests that, despite acknowledgment of issues specific to AYAs with cancer and their family members, there is little understanding of best practice models which address the specific issues associated with this forgotten population.

The resources required to implement the National Delivery Framework and the recommendations from the OnTrac Practice Framework, requires time and money as the health system slowly develops an awareness of this forgotten group of people (CanTeen and Cancer Australia, 2009; Palmer & Thomas, 2008). In 2009 the Commonwealth Government in Australia committed $15 million dollars over three years for the establishment costs of Youth Cancer networks in Australia to support and care for AYAs with cancer and their families (Herron, 2008). Despite this commitment, CanTeen needs to conduct an advertising campaign to the Australian public to donate old mobile phones in order to raise additional funds to augment this commitment.

The $15million to develop these services could almost be seen as tokenistic with significantly more resources required to develop the service outlined in the National Delivery Framework. The National Delivery Framework identified the following barriers to improved service delivery: lack of consistent and accessible data, inadequate evidence on new approaches, un-determined impact on workforce, unclear career development pathways, fragmented website information, lack of dedicated and coordinated resources, lack of evidence of AYA outcome, service quality and effectiveness (CanTeen and Cancer Australia, 2009).

Given these barriers, the insights from this study, and in the absence of an identified best practice model, as identified by Ferrari et al (2010) the following needs to be considered when developing best practice models for care for AYAs and their families.
Cancer Landscape - Departure, Exploration and Anticipation Stage

There is a need to acknowledge that AYAs and their families are a unique group of people and care should be delivered in age appropriate ways, which recognise their developmental needs.

The recognition of the importance of family for the AYA raises the need for a family psychosocial assessment conducted at diagnosis, with suitable interventions that are reviewed regularly.

In order to prevent delay in diagnosis an increased awareness is required, concerning cancer in AYAs, for primary health care professionals and the general public.

When communicating with AYAs and their families, information should be given in an empathetic way that is understandable and age and developmentally appropriate for the AYA and their family.

Within this communication framework AYAs and family members should be informed of the treatment and any possible anticipated and unanticipated effects of treatment.

The AYAs and the families should be provided with a map of what to do in the event of the possibility of unanticipated effects of treatment.

There needs to be recognition that the cancer landscape is an isolating experience for the AYA and their family, and that all attempts should be made for AYAs to maintain links with their peers.

Normalcy is important for an AYA within the cancer landscape and wherever possible allowances should be made to ensure that the AYA cancer patient can engage in and maintain as normal a life as possible.

Within the hospital landscape, health care professionals should be mindful of AYAs isolation and displacement within the system and seek ways to understand and alleviate some of these issues.

To alleviate some of this isolation, efforts should be made for AYAs and families to be connected with other AYAs and families who are part of the cancer landscape.
The AYA and the family’s care needs to be coordinated through a case manager to ensure care is consistent and health care professionals involved in the care have relevant medical, developmental and psychosocial information.

Adequate financial, social and practical support needs to be provided to family members in order for them to stay connected and support the AYAs through the cancer journey.

There should be an understanding by all involved that the typical hospital landscape is not therapeutic and there needs to be in place creative solutions that provide a more healing landscape for the AYA and family.

There needs to be an acknowledgement that family members wish to be engaged in the AYAs’ care and at times provide a 24/7 physical presence. The hospital landscape needs to provide a place and space for this to occur.

Given the horrors associated with treatment and the possible development of psychological disorders, emotional and psychological support needs to be provided to the AYA and the family to create some meaning from the experience.

**Dying Landscape - Destination Stage**

Palliative care best practice frameworks need to recognise AYAs as a defined population with unmet needs at the end of life.

Within the dying landscape therapeutic landscapes need to be created that provide support for the AYA and the family.

End of Life discussions need to be initiated early for informed choices to be made about the how, when and where to manage the dying trajectory.

Regular communication is required between cancer services and palliative care to ensure that referral to palliative care is made sooner rather than later for symptom management during the dying trajectory.

More practical support needs to be available for AYAs dying at home so that the family does not become overwhelmed with the burden of care.

A coordinated approach is required through palliative care, with families and primary health care practitioners able to access health care professionals with expertise in dying to alleviate the suffering associated with the dying trajectory.
There should be an identified case manager with palliative care expertise who coordinates care and communicates with health providers on best practice methods for the dying trajectory.

Recognition of the intense emotional involvement associated with the dying trajectory for the AYA and the family should be acknowledged and families given an opportunity to express these feelings.

Families are given the opportunity and time to maintain a living connection with the AYA after death in order to say goodbye.

**Further Research**

The study sought to understand this experience of the AYA cancer journey from the perspective of family members. The study covered the whole cancer journey from the time the first signs and symptoms were noticed through to the time of death and immediately afterwards. The stories in this study identified gaps in the system and in health care professionals’ knowledge on how to care for AYAs and their families. In addition the stories provide an in-depth understanding of the horror and suffering that the AYA and the family endured in our present cancer landscape.

There is beginning research on unmet needs for AYAs with cancer (Patterson, et al., 2008a). However, there has, however, only been one similar study to this study (Grinyer, 2002a, 2004b, 2006a, 2008; Grinyer & Thomas, 2001) which examined the experience from the parents’ perspective using a narrative correspondence method. This particular study mainly focused on life stage issues for the AYA and the family member. At present there is limited qualitative and quantitative research that specifically targets the AYA group indentified in this study (Grinyer, 2007b; Millar, Patterson, & Treadgold, 2008; Patterson & Millar, 2008; Patterson, et al., 2008a). Therefore, from the experiences of the family members in this study, and the limited research in this area, further research is required on: health care professionals’ understanding and knowledge of AYAs and their families; effective communication with AYAs and their families; how to support the AYAs and the families through the cancer journey; how to provide a therapeutic landscape to care for AYAs, and their families; and, how to support AYAs and their families psychologically and physically.
during the dying trajectory. In particular further research is required in the development of best practice models. These models are required to determine the specific physical, developmental, psychological and social requirements that would provide a therapeutic landscape for AYAs and their families. A combination of quantitative and qualitative research paradigms are required to further advance the body of knowledge on best practice models of care.

LIMITATIONS AND STRENGTHS OF THE STUDY

The following limitations are associated with narrative inquiry: the retrospective nature of the study, the length of time for analysis and presentation of findings, and the blurring of interpretative boundaries (Riley & Hawe, 2005). The family members’ reconstructions of the experience are not true replicas of events - they are selected elements of the experience that create meaning for the family member (Bruner, 1987; Lee & Poole, 2005; Mishler, 1986a, 1986b; Riessman, 1993; Sandelowski, 1991, 1993). Narrative inquiry only captures the experience at a certain point in time and the interrelation of the experience can change over time (Frank, 1997; Lee & Poole, 2005). Narratives are constructed by both the researcher and the family member in that the questions asked influence and shape the content and direction of the story (Lee & Poole, 2005) which can create a problem of rigour for the research (Bruner, 1987) to the extent that narrative become truthful fiction (Overcash, 2004). This concept, of how the story is constructed and truthful fiction, extends into transcribing, analysing, and reading, the boundaries of a story, or what part of the narrative the researcher includes in the final narrative.

Narrative is not a truth because elements of the story can be expected to change from the telling to the final interpretation (Sandelowski, 1991). The meta story is the narrative created by the researcher through the stories of others (Gilbert, 2002). This meta story has in turn been interpreted through the methodological framework chosen for this study and there are other methodological frameworks for interpreting the stories (Lee & Poole, 2005; Lieblich, et al., 1998).

In addition the family members in this study self selected and are not a representative sample. This self selection was influenced by the family member’s knowing that the I had a similar experience to their own. Compounding these limitations is my own
experience of her adolescent son dying of cancer. Therefore, as with other qualitative research methods, findings from this study cannot be generalised. However, the purpose of this study was to understand the experience of the family members during the cancer journey with an AYA family member. The analysis and interpretation of the stories in this study revealed recurring themes suggesting a commonality of experience for the family members in this study.

The family members in this study all wanted to tell their stories in order that others could understand the suffering and pain that their loved one endured, and how they struggled to provide the nurturing and care that their loved one deserved within the present system of care. While I had positioned myself as both a researcher and mother to the family members, the family members felt free and safe to tell rich stories of their experience to someone who really understands (their words). During the interpretations and analysis, it was important for me to honour the family members’ stories. I was mindful that the family members had trusted me with extremely painful experiences that would otherwise remain undocumented and unheard. Grinyer (2002a) believes that these experiences are required to be treated with integrity and sensitivity and not exploited for the advancement of an academic career or for the benefit of others involved in the research and publication process. With this in mind the stories were analysed and interpreted through the lens of my understanding of the family members’ experience and a knowledge that I was entrusted with extremely sensitive stories. For this reason this study includes all the core stories, four within the thesis and the remaining in the appendices. Whilst these stories may be considered long for academic purposes, I felt it important to include them as a testament to the family members and the AYAs.

**FINAL WORDS**

From the researcher’s perspective the vision for the future for these young people and their families is that the community demonstrates the same concern and compassion for these young people and family members, as that which is observed with children and children’s families with cancer. This can only be achieved through further knowledge and understanding of this group of people. This vision requires that the care of AYAs with cancer and their families becomes a national priority. The establishment of a Centre of Excellence, with adequate funding to research the unique issues for AYAs and their families is the first step to acknowledging this forgotten group. A Centre of
Excellence would provide best practice guidelines for AYAs and their families. As part of this national priority discrete services established for AYA and their families should demonstrate the application of these best practice guidelines and coordinate the care of AYAs and their families throughout the cancer journey.

Finally, the process of writing this thesis was been both painful and enlightening as I heard, listened to and analysed the stories. The stories spoke of sacrifice and courage in the face of overwhelming pain and suffering. All were testaments to how the human spirit deals with the horror of cancer, its treatment and the eventual death of a loved young family member. The experience left me humbled and inspired as the family members shared their painful and courageous experiences with me. The core stories and meta-narrative in this study reveal that the experience and needs of AYAs and family members need to explored in more detail by health systems and health professionals to ensure appropriate care for this group of people.

Anthony’s words:

Mortality is a blessing taken without recognition.

We all walk the same tightrope

Only some dare to look down, whereas others have to.

There is only one thing we can do: try not to walk the rope alone.

Anthony Barling (2002)
REFERENCES


Blumenreich, M. (2004). Avoiding the pitfalls of 'conventional' narrative research: Using poststructural theory to guide the creation of narratives of children with HIV. *Qualitative Research, 4*(1), 77-90.


CanTeen. (October 26th 2007). *Media Release: Adolescent and Young Adult (AYA) cancer services*.


Grinyer, A. (2002b). The anonymity of research participants: Assumptions, ethics and practicalities. Social Research Update (36), University of Surrey.

Grinyer, A. (2004a). The narrative correspondence method: What a follow up study can tell us about the longer term effects on participants in emotionally demanding research. Qualitative Health Research, 14(10), 1326-1341.


Hurwitz, C., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life: "There are people who make it, and I'm hoping to be one of them". *Journal of the American Medical Association, 292*(17), 2141-2149.


Joint Working Party on Palliative Care for Adolescents and Young Adults. (2007). *Palliative care for young people aged 13-24 years*. Bristol: ACT.


Klopfenstein, K., & Young-Salame, T. (2002). Your role in the spectrum of adolescent cancer: Diagnosis through treatment to care at life's end. *Contemporary Pediatrics, 19*(8), 105-118.


resources of young people with cancer. *European Journal of Cancer Care, 10*(1), 6-11.


APPENDICES
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<th>Treatment</th>
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<td>Feb 2001</td>
<td>Girlfriend notices lump on side of chest; suggests Ant talks to parents.</td>
<td>Anthony makes appointment with local GP who refers for a Ultrasound.</td>
<td>Ultrasound report describes lump as probably benign.</td>
<td>Nothing of real concern on our radar – our families have no history of cancer.</td>
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<tr>
<td>March 2001</td>
<td>Back to GP who offers 3 choices: cut it out; watch it and see if it grows, or; have a needle biopsy.</td>
<td>Needle biopsy undertaken guided by ultrasound, two days after Anthony’s 16th birthday.</td>
<td>Called by GP surgery and asked to come in the next morning and allow time for further scans.</td>
<td>Very anxious wait, thinking this is not good news.</td>
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<td>March 2001</td>
<td>GP registrar tells us that Anthony has a rare cancer called Rhabdomyosarcoma and needs to have a CT scan and bone scan and go to Sydney for treatment.</td>
<td>CT scan shows that the tumour is 3.2cm in diameter.</td>
<td>Diagnosis of Rhabdomyosarcoma.</td>
<td>Janet (mother) refers to an old medical text to find that this is a rare type of paediatric cancer which grows quickly and metastasises early. Absolutely devastated and scared.</td>
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<tr>
<td>March 2001</td>
<td>Flew to Sydney RPA hospital for appointment with surgeon and medical oncologist. Oncologist is optimistic about a cure as the tumour is encapsulated and no evidence of any spread.</td>
<td>Explained that the treatment will involve 4 cycles of chemotherapy to shrink the tumour then surgery to remove what remains of the tumour and resect the chest wall, 2 more cycles of chemotherapy to ‘mop up’ any remaining microscopic cancer cells.</td>
<td>As treatment may cause infertility Anthony is referred to the Androgyny Clinic at Concorde Hospital for sperm collection. Three samples collected over 4 days. Good swimmers reported!</td>
<td>Confronting the challenges of what the treatment will do.</td>
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<td>March 2001</td>
<td>First chemotherapy treatment at RPA.</td>
<td>Chemotherapy (three different drugs): Doxorubicin, Vincristine, Cyclophosphamide.</td>
<td>Some nausea and loss of appetite.</td>
<td>This is really happening.</td>
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<td>April-May</td>
<td>Second at RPA, Third and Fourth Cycles of Chemotherapy at Lismore Base Hospital, Cancer Care Unit three weeks apart.</td>
<td>OCAVAC then VAC. GCSF (Neupogen) injections daily after chemo to stimulate cell production.</td>
<td>Some nausea, lack of appetite, loss of hair, mouth ulcers.</td>
<td>Tumour shrinking from 6x6cm to 4x3cm by 11/4/2001.</td>
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<tr>
<td>April 2001</td>
<td>PET scan at RPA to check if disease had spread before chemo treatment</td>
<td></td>
<td>Relief that it doesn't appear to have spread.</td>
<td></td>
</tr>
<tr>
<td>May 2001</td>
<td>Ant attends ‘patient member’ weekend with CanTeen on Sunshine Coast.</td>
<td></td>
<td>Meeting other patient members a good experience for Anthony.</td>
<td></td>
</tr>
<tr>
<td>June 2001</td>
<td>Removal of tumour at RPA, the day after Melanie (sister) returns from</td>
<td>Chest resection removes remains of tumour, two ribs and the nerves on the</td>
<td>Surgeon is happy with the surgery, said it was hard to find the tumour as it had shrunk so much with chemotherapy. Oncologist later advises that pathology on the tumour showed a 98% kill rate of the cancer cells with chemotherapy.</td>
<td>High anxiety about the surgery mixed with anticipation that this would save Anthony’s life. So very thankful that we have good friends in Sydney who look after us in so many ways.</td>
</tr>
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<td></td>
<td>overseas. Discharged from RPA after 6 days to friends house in Sydney for convalescence.</td>
<td>underside of the ribs. Returns to ward with chest tube in. PCA effective and moved to oral analgesia within 3 days.</td>
<td></td>
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<tr>
<td>June 2001</td>
<td>Return home to Alstonville.</td>
<td>Recovering from major surgery.</td>
<td>Sense of relief that the tumour was no longer there and feeling positive about a cure. Great to be home.</td>
<td></td>
</tr>
<tr>
<td>July-August 2001</td>
<td>Chemotherapy at Lismore Base Hospital. Ant attends a CanTeen film-making weekend in Sydney sponsored by Sony.</td>
<td>2 more cycles of chemo at Lismore.</td>
<td>Confident that this would ensure a cure. Great to see Ant enjoying a fun and learning activity.</td>
<td></td>
</tr>
<tr>
<td>October 2001</td>
<td>Chest CT Scan to check for any regrowth.</td>
<td>CT scan reveals no tumours.</td>
<td>Enormous relief that this was the first step to a cure. If still clear in 2 years then Ant is considered to be cured.</td>
<td></td>
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<tr>
<td>November 2001</td>
<td>Anthony experiences back pain which we put down to muscle strain from going body boarding too soon.</td>
<td>Visit to GP results in removal of a small mole on scar line.</td>
<td>Mole removed, no big deal.</td>
<td>Not really worried.</td>
</tr>
<tr>
<td>November 2001</td>
<td>Back pain continues to get worse. Surgeon contacted and advised us to get a bone scan.</td>
<td>Bone scan and CT scans carried out at Lismore and results taken immediately to GP for advice.</td>
<td>Scans reveal metastases in the left knee. GP advised us to have a Christmas to remember!</td>
<td>Sheer terror and despair.</td>
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<tr>
<td>December 2001</td>
<td>Urgent trip to RPA to consult with Oncologist whose first words as the family walked towards him down the corridor were “oh hell” as his shoulders slumped. We are advised that they could simply treat the symptoms and make Ant comfortable or they could try another treatment which might involve high dose chemotherapy and stem cell transplant. After some hesitation Anthony decides to opt for more treatment.</td>
<td>PET scan carried out on 11/12 at RPA to determine extent of metastasis. This is a one and a half hour procedure involving medication to keep the patient still, catheterisation, and then injection of a glucose reactive isotope which shows areas in the body where the glucose is taken up by the cancer. It is an expensive procedure (approx $3,000 – covered by Medicare) but the best at detecting cancers in all parts of the body.</td>
<td>PET scan report: “There has been a rapid progression of disease with multiple glucose avid lesions consistent with disseminated metastases ... throughout the vertebral column, the left lower lung lobe and in the distal femur”.</td>
<td>Absolute devastation and huge anxiety for family. Trying not to be down in front of Anthony – he doesn’t need to witness our fear and grief.</td>
</tr>
<tr>
<td>December 2001</td>
<td>Referred to Royal Brisbane Hospital (RBH) for radiotherapy.</td>
<td>Needed to get an MRI for radiation planning – unable to get one quickly at RBH so went to Greenslopes Private Hospital. Anthony in significant pain. Results of Sydney PET scan sent to RBH. At major risk of cord compression. Radiation commenced on chest, spine and knee.</td>
<td>MRI results: “Multiple metastases identified the most marked are at T3 and T5 where there is extradural extension of disease causing mild cord compression ... both have a high likelihood of causing cord compression in the near future”.</td>
<td>Alarm at prospect of cord compression and need to deal with the increasing pain levels.</td>
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<tr>
<td>December 2001</td>
<td>Radiation planned, marking up his body for the radiation therapists.</td>
<td>Radiotherapy: 28 Grays over ten sessions with a break on Christmas and Boxing day.</td>
<td>Radiation Oncologist states at the end of treatment that there is not much more they can do. They could try more chemo but this was unlikely to work as it is a very aggressive cell.</td>
<td>Another kick in the guts. Joyous moment when Ant meets the John Butler Trio at Woodford 27/12, arranged by CanTeen.</td>
</tr>
<tr>
<td>28 December 2001</td>
<td>Flew from Brisbane to Sydney immediately after the final radiation treatment to see Oncologist.</td>
<td>Agreed to refer Anthony to RBH for chemotherapy. Gives some chemotherapy as some metastases were not treated with radiation.</td>
<td>Chemotherapy without the agent that would exacerbate the radiation effects on throat.</td>
<td>Sense of relief that something was finally being done about the metastasis not previously treated.</td>
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<td>January 2002</td>
<td>Home in Alstonville.</td>
<td>Advised by RBH radiation oncologist to get a naso-gastric (NG) tube inserted to feed him.</td>
<td>Effects of radiation therapy appear and make swallowing difficult – radiation burns to oesophagus.</td>
<td>It is OK to deal with side effects – the important thing is that the treatment works.</td>
</tr>
<tr>
<td>January 2002</td>
<td>Visit to Emergency Dept at Lismore Base to have an NG tube inserted.</td>
<td>NG tube inserted.</td>
<td>Taking nourishment through NG tube.</td>
<td>Feeling like this is just a stage and it will pass.</td>
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<tr>
<td>February 2002</td>
<td>Unable to eat. Vomited out the NG tube.</td>
<td>Visit to Emergency Dept at LBH. NG tube reintroduced and given some fluids as we are in the middle of a heatwave.</td>
<td></td>
<td>Worried at first about reinserting the NG tube but Medazalin made it simple and a good CMO on duty.</td>
</tr>
<tr>
<td>February 2002</td>
<td>Unable to take nourishment without feeling sick.</td>
<td>Weekend home visit from GP after hours.</td>
<td>No real outcome, bowel sounds normal?</td>
<td>Frustration – something not right.</td>
</tr>
<tr>
<td>February 2002</td>
<td>Admitted to children’s ward at Lismore Base.</td>
<td>Enema to treat constipation and to re-establish feeding.</td>
<td></td>
<td>Relief that we were in capable hands and things would start to improve.</td>
</tr>
<tr>
<td>February 2002</td>
<td>Return to Royal Brisbane for Medical Oncology appointment.</td>
<td>Decision made to treat from the beginning using standard Rhabdomyosarcoma protocols with a view to moving to high dose chemo and stem cell transplant.</td>
<td>Need to arrange to have a Port-a-cath inserted in upper chest.</td>
<td></td>
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<tr>
<td>March 2002</td>
<td>Day surgery at St Vincent’s Private Hospital in Lismore to install port-a-cath.</td>
<td>Port-a-cath makes it easy to access the blood system without having to find a vein.</td>
<td></td>
<td>Another stage in the journey that should make things easier for treatment not having to find and cannulate a vein in the arm.</td>
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<tr>
<td>March-May 2002</td>
<td>Chemo treatments.</td>
<td>Bone scan, CT scan and bone marrow biopsy first to establish baseline.</td>
<td>Oncologist comments that in the early days with the rapid spread of the disease there was not much optimism, but now very impressed with response to treatment.</td>
<td>A glimmer of hope maybe? Hospital in Brisbane is draining. Ant can’t wait to get out. Doesn’t listen to music because he doesn’t want to associate it with this experience. The wards are old and he is mixed with much older men – very depressing.</td>
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<tr>
<td>March-May 2002</td>
<td>Admitted to Children’s ward at LBH, neutropenic and spiking a temperature. (three times after inpatient chemotherapy at RBH).</td>
<td>Blood cultures taken and strong antibiotics started to treat potential infection.</td>
<td>A few days in hospital until temperature returns to normal, blood transfusions and then discharge.</td>
<td>This is routine.</td>
</tr>
<tr>
<td>May 2002</td>
<td>Appointment with Oncologist at RBH. The nuclear medicine specialist on the paediatric team from Royal Children’s Hospital which is ‘directing’ Ant’s treatment wants Ant to have another PET scan because he saw something in his hip. Request that this be done in Sydney at RPA where previous scan had been done. (despite the fact that there was a PET scanner at the Wesley in Brisbane).</td>
<td>Family travels to Sydney: First PET scan attempt aborted after the isotope failed to turn up. Second attempt OK.</td>
<td>Results of the PET scan were negative about hip involvement. OK to proceed to autologous stem cell collection.</td>
<td>Not sure why we are all in Sydney when this could have been done in Brisbane. Never find out the real reason for this.</td>
</tr>
<tr>
<td>May 2002</td>
<td>Return to Brisbane for appointment with Oncologist and MRI on knee. Results of the PET scan were negative about hip involvement and MRI was cancelled. Medical Oncologist advises that Bone Marrow Transplant is a ‘now or never’ treatment option. But we must understand that this is not a cure (in other cancers eg Leukaemia) it is given as a consolidation treatment when a person is in remission. Anthony is not in remission.</td>
<td></td>
<td>Relief that there is no hip involvement and hope that the next treatment might produce some sort of miracle. Although we ‘hear’ that this is not a cure it is the only hope of Ant having more time. He doesn’t focus on the ‘no cure’ statement so why should we.</td>
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<tr>
<td>May 2002</td>
<td>Harvesting of stem cells at RBH.</td>
<td>Collection of Anthony’s stem cells over three days. Spending about 5 hours a day hooked up to an aphaeresis machine which takes blood and centrifuges the stem cells for collection.</td>
<td>Eventually enough stem cells are harvested to enable a stem cell transplant to take place after high dose chemotherapy.</td>
<td>Relief that despite all previous chemo treatments they were able to harvest enough stem cells to allow the transplant to go ahead. Happy that things are on track.</td>
</tr>
<tr>
<td>June 2002</td>
<td>Referral to Bone Marrow Transplant Specialist. He wants to know what we have been told. Emphasises that this is not a cure but a chance of remission for between 6 months – 5 years. At the end of the appointment he says he can get Ant walking for his Year 12 formal after the stem cell transplant.</td>
<td>Admission to Brisbane Private Hospital for insertion of Hickman Line and commencement of high dose chemotherapy (Melphalan &amp; Busulfan) to totally wipe out Anthony’s immune system. Transfer to Bone Marrow Transplant Unit at RBH. When white cell count is zero, Anthony’s own stem cells are transfused back into his body.</td>
<td>No hair at all not even eyebrows. On crutches for knee. Being fed intravenously. A total of 5 drips on 5 pumps going through the Hickman line and port-a-cath. In hospital for 3 weeks with limited visitors and having to wash hands and gown up before entering his ‘cell’ for the next 3 weeks.</td>
<td>Waiting for the cell count to go down to zero and then after transplant willing it to come up. Some optimism that this treatment will give Anthony some more time but not a cure – try not to focus on the last bit.</td>
</tr>
<tr>
<td>July 2002</td>
<td>Return home to Alstonville to recuperate.</td>
<td></td>
<td>Great to be back in our own space.</td>
<td>Respite</td>
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<tr>
<td>Sept 2002</td>
<td>Anthony attends Alstonville High School Year 12 final assembly as Boys Vice Captain. One of the few times he has attended school in 2002.</td>
<td>Admitted to private hospital for surgery but when Surgeon looks at scans of his knee he asks “how long has he got” and “his knee is like the twin towers and could collapse at any time”. The surgery is beyond him so he refers us to another specialist surgeon.</td>
<td>Admitted overnight and discharged the next day with no surgery.</td>
<td>We are so proud of the way Ant has conducted himself. Although he hasn’t attended any classes this year he is chuffed at being Boys Vice Captain. To see him up on the stage and hear the cheers of his classmates and staff is emotional for us.</td>
</tr>
<tr>
<td>Sept 2002</td>
<td>Referral from Bone Marrow Specialist to Orthopaedic Surgeon to ‘repair’ the knee – Anthony has been on crutches since April.</td>
<td></td>
<td></td>
<td>At least Ant gets to attend his Pa’s 80th birthday celebration.</td>
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<td>8 October 2002</td>
<td>New orthopaedic surgeon notes that this is not curative but may provide more time. Bone marrow transplant doctor asks us to get a chest x-ray before coming to Brisbane. Total Knee Replacement surgery at The Wesley hospital in Brisbane.</td>
<td>Chest X-ray reveals a major pleural effusion in the left lung. On arrival at The Wesley Hospital we find the haematologist and show him the chest X-ray. He consults the anaesthetist and returns with the words that the anaesthetist believes he will be &quot;OK for the surgery&quot;. Total Knee Replacement operation goes ahead.</td>
<td>&quot;The distal third of the femur has been resected and a reconstructive prosthesis is in place. The patella has been preserved.&quot; Surgeon visits after Antony returned to ward to tell us that the surgery went OK but that his lung is probably of most concern. The day after surgery they take Ant to radiology and drain one and a half litres of blood stained fluid from his chest.</td>
<td>Too scared to ask what is happening. What is causing the pleural effusion? Later we realise that this operation was sheer folly and should not have been carried out. Feelings of guilt that we didn't protect Ant mixed with anger at the system that allowed it to go ahead. We run into his Medical Oncologist who said &quot;what is going on? – he should be at home&quot;.</td>
</tr>
<tr>
<td>28 October 2002</td>
<td>Return home and Anthony is taken out by his friends on Bandana Day in the back of a station wagon to watch them do some fire-twirling.</td>
<td>Another highlight in an otherwise year packed with tests and treatment for Ant.</td>
<td></td>
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<td>November 2002</td>
<td>Ambulance called to take Anthony to Lismore Base ED suffering shortness of breath.</td>
<td>Another litre of fluid drained from chest and admitted to Children’s ward with drain in situ. After a few days it is decided to try a pleuradesis procedure to stop the fluid build up.</td>
<td>Pleuradesis performed in theatre and surgeon tells us that Anthony’s left lung is just full of tumour. Physician talks to us about palliative care. Time to go home.</td>
<td>Realisation that the end is approaching. Contact the RBH oncologist for any last chance treatment – nothing on offer.</td>
</tr>
<tr>
<td>November 2002</td>
<td>Ambulance called to take Ant to St Vincent’s palliative care due to shortness of breath.</td>
<td>Chest X-ray shows no left lung capacity.</td>
<td>Sent home with an Oxygen Concentrator and daily nursing visits organised between Palliative Care on weekends and Community Nursing weekdays.</td>
<td>Life is so cruel. We want Ant to die at home – he has spent too much time in hospitals. We try and be strong for him. He doesn’t want to talk about his approaching death much to my dismay. I raise it with him the day before he dies but he said &quot;I’m not going anywhere, I have too many things I want to do&quot;.</td>
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<tr>
<td>November</td>
<td>Ant decides he wants to go to Byron Bay to attend a birthday party for 2 girlfriends from school. Wheelchair and Oxygen tank required.</td>
<td></td>
<td>Ant happily declares as we leave the party “that went as well as could be expected”. We regret that we couldn’t give him more good times but the treatment was relentless and debilitating over the last 12 months.</td>
<td>It is good that Ant can spend some time with friends – very precious and to see him smile is wonderful but so sad at the same time.</td>
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<td>2002</td>
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<td>30 November</td>
<td>Following several days of not eating, occasionally sucking on ice, pain patches and Rivotril to reduce anxiety, plus occasional ‘hashish’ drops help ease the situation. Towards the end there were conversations with members of the family - while not directly admitting he was dying he was able to talk about special times he’d had with people. He likes to be carried to different locations in our house – the couch, our bed, his bed. On this day I tell him no moving today as my back is very sore from the lifting. This is OK with Ant.</td>
<td>Lying on his bed in his room, dozing. Ant complains that his back is ‘caning’. Janet (mother) gets on the bed to rub his back; Mel (sister) is also in the room with me. Janet calls out ‘Bruce’; I turn and see that Anthony’s eyes are fixed. Mel says will I get Glen (brother) just as he walks into the room. We are all together, including the dogs Tess &amp; Mickey. Ant has taken his last breath and it happened so quickly without fuss – just like him to slip away like this. We all touch his body and cry and profess our love. It is 1.20pm. We open the windows in his room, and play JBTs ‘Ocean’ really loud. We toast him with champagne. Later we all bathe him, shave his stubble and dress him in his cool clothes. The GP is called and signs the death certificate. The undertaker comes later in the afternoon and zips him up in a black bag and takes his body away on a trolley.</td>
<td>Pain and suffering is no more for Anthony – almost blessed relief, We who are left behind will carry it now. This will let Ant’s spirit leave and rise up and be free at last! We are all alone. This is the end of a long and painful journey for Ant and our family. It is also the start of another journey of our profound grief and how we remember Anthony and keep him a part of our family.</td>
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**SUMMARY OF TREATMENTS:** Anthony was under the care of some of the best clinicians and health services that Australia has to offer. Over a twenty month period Anthony received care or treatment in 4 public and 3 private hospitals both in NSW and Queensland. This encompassed 12 cycles of chemotherapy, 28 Grays of radiation, 2 major surgeries, 3 minor surgeries, an autologous stem cell transplant, 3 PET scans, 4 MRIs, 7 CT scans, 4 Bone Scans, 20 chest X-rays, 2 bone marrow biopsy’s, and about 15 transfusions of irradiated packed cells. In total he spent close on three months in hospitals as an inpatient, mostly in 2002. It would have been wonderful to have a single ‘case manager’ helping us to navigate the health systems. We were effectively the co-ordinators of Anthony’s care and we could only do this because we had the education, knowledge and resources, plus understanding employers. Our only regret is the total knee replacement – we really needed someone else who could see the big picture and question ‘why are we doing this?’
Appendix B: Ethics approval
HUMAN RESEARCH ETHICS COMMITTEE

At the meeting of the Human Research Ethics Committee, held on 5/12/05 your application was considered by the HREC.

This application has been approved by the HREC subject to the following standard conditions.

The Committee commended this application. Would the researchers give permission for this application to be used as an exemplar in the future? The Secretary is always chasing good applications to use as examples for other researchers.

**Standard Conditions** (in accordance with the Guidelines of the NHMRC National Statement on Ethical Conduct in Research Involving Humans):
1. That the principal investigator/person responsible (usually the Supervisor) provide a report every 12 months during the conduct of the research project specifically including:

(a) The security of the records.
(b) Compliance with the approved consent procedures and documentation.
(c) Compliance with other special conditions.
(d) Any changes of protocol to the research.

Note: Compliance to the reporting is mandatory to the approval of this research.

2. That the person responsible and/or associates report and present to the Committee for approval any change in protocol.

3. That a report is sent to HREC when the project has been completed.

4. That the person responsible and/or associates report immediately anything that might affect ethical acceptance of the research protocol.

5. That the person responsible and/or associates report immediately any serious adverse events/effects on participants.

6. That the person responsible and/or associates report immediately any unforeseen events that might affect continued ethical acceptability of the project.

7. That, if this research is conducted in a country other than Australia, all research protocols for that country are followed ethically and with appropriate cultural sensitivity.

8. That Participants be advised in writing that:

*The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The Approval Number is ECN-05-146. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms Suze Kelly, (telephone (02) 6626-9139 or fax (02) 6626 9145, email: skelly1@scu.edu.au)*

*Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.*
Suzanne Kelly
Secretary, HREC
Ph: (02) 6626 9139
skelly1@scu.edu.au

Dr Baden Offord
Chair, HREC
Ph: (02) 6620 3162
rofford@scu.edu.au
Appendix C: New Ethics approval
HUMAN RESEARCH ETHICS COMMITTEE (HREC)
NOTIFICATION

To: Professor Bev Taylor
Department of Nursing and Health Care Practices
bev.taylor@scu.edu.au, jan.barling@scu.edu.au

From: Secretary, Human Research Ethics Committee
Graduate Research College, R. Block

Date: 18 April 2008

Project: From Go to Woe: Families Stories of adolescents and young people living and dying from cancer.

Status: Old Approval Number ECN-05-146
New approval number ECN-08-029
Change of protocol approved at HREC

Thank you for the notification of changes in protocol for the above project. The HREC has noted that some participants wished their names to be used and not a pseudonym and the HREC has approved this change. It is noted that this research study does not have a current ethics approval number. As in the standard conditions, ethics approvals should be renewed every 12 months.

Therefore, I have issued this study with a current approval number of ECN-08-029. Please note this in all your correspondence and please note any other changes from the standard conditions, such as the address for the Ethics Complaints.

Please, in future, renew this research annually.

Standard Conditions in accordance with the National Statement on Ethical Conduct in Human Research (National Statement) (NS).
1. Monitoring

**NS 5.5.1 – 5.5.10**

Responsibility for ensuring that research is reliably monitored lies with the institution under which the research is conducted. Mechanisms for monitoring can include:

(a) reports from researchers;
(b) reports from independent agencies (such as a data and safety monitoring board);
(c) review of adverse event reports;
(d) random inspections of research sites, data, or consent documentation; and
(e) interviews with research participants or other forms of feedback from them.

The following should be noted:

(a) All ethics approvals are valid for **12 months** unless specified otherwise. If research is continuing after 12 months, then the ethics approval MUST be renewed.

(b) **NS 5.5.5**

   Generally, the researcher/s **provide a report every 12 months** on the progress to date or outcome in the case of completed research specifically including:
   - The maintenance and security of the records.
   - Compliance with the approved proposal
   - Compliance with any conditions of approval.
   - Any changes of protocol to the research.

Note: Compliance to the reporting is **mandatory** to the approval of this research.

(c) Specifically, that the researchers **report immediately** and notify the HREC, in writing, for approval of any change in protocol. **NS 5.5.3**

(d) That a report is sent to HREC when the **project has been completed**.

(e) That the researchers **report immediately any circumstance** that might affect ethical acceptance of the research protocol. **NS 5.5.3**

(f) That the researchers **report immediately any serious adverse events/effects on participants**. **NS 5.5.3**

2. Research conducted overseas

**NS 4.8.1 – 4.8.21**

If research is conducted in a country other than Australia, **all research protocols for that country** are followed ethically and with appropriate cultural sensitivity.

3. Complaints

**NS 5.6.1 – 5.6.7**

Institutions may receive complaints about researchers or the conduct of research, or about the conduct of a Human Research Ethics Committee (HREC) or other review body.
Complaints may be made by participants, researchers, staff of institutions, or others. All complaints should be handled promptly and sensitively.

*Complaints, in the first instance, should be addressed in writing to the following:*

Ethics Complaints Officer  
Graduate Research College  
Southern Cross University  
PO Box 157  
Lismore, NSW, 2480  
sue.kelly@scu.edu.au

*All complaints are investigated fully and according to due process under the National Statement on Ethical Conduct in Human Research and this University. Any complaint you make will be treated in confidence and you will be informed of the outcome.*

*All participants in research conducted by Southern Cross University should be advised of the above procedure and be given a copy of the contact details for the Complaints Officer. They should also be aware of the Ethics Approval Number issued by the Human Research Ethics Committee.*

Sue Kelly  
Secretary, HREC  
Ph: (02) 6626 9139  
sue.kelly@scu.edu.au

Associate Professor B. Offord  
Chair, HREC  
Ph: (02) 6620 3162  
Baden.offord@scu.edu.au
Appendix D: Two local newspaper articles
Mother uses PhD to help teenage cancer patients

After watching her teenage son die of cancer, a woman has joined the fight by helping people who work with young people to come to terms with what they are going through. She used her PhD work to turn her studies on young people with cancer into a website for parents and carers. She works in a hospital and is now working on something to help new patients and their families cope with the experience of their own child having cancer. She is working to help parents understand the experience of their child and to help them get through the experience of having a child with cancer.
Mum finds research topic in son's death from cancer

Teenagers undergoing treatment are caught between two worlds, says uni researcher

By ZOE SATHERLY

WHEN Jan Barling lost her teenage son to cancer, she came face-to-face with the glaring inadequacies of the health system in dealing with the special social and emotional needs of teenagers. The Southern Cross University researcher discovered that her son, Anthony, like all teenage cancer patients, was caught between worlds. Anthony was too old for the children's ward, with its fairy-tale wallpaper and bunnies on the wall, yet out of place in the adult ward, where the majority of patients are old and frail.

Now Jan is undertaking research that might help address the needs of teenage cancer patients.

"I hope my research will eventually be used to give the health system and health professionals an insight into the special needs of teenagers with cancer, and enable them to change hospital procedures so that teenagers are placed in more age-appropriate environments, rather than having them dumped in an environment which contributes to their despondency," Jan said.

Jan said research showed the teenage cancer rate was increasing more than any other age group. Nearly twice as many 12 to 24-year-olds are diagnosed with cancer as children under 12, and teenage survival rates are behind those of any other age group.

"That is another reason why teenagers need extra care and attention paid to their mental and emotional wellbeing during treatment," said Jan, who lectures in mental health and nursing.

"Teenagers having cancer treatment need to feel positive and uplifted, which is impossible to achieve when they are in adult wards among much older people who have different issues and concerns to themselves."

Jan said Anthony's death from a muscle tumour had devastated the family as he had had major surgery and months of chemotherapy. The tumour had been successfully removed and he appeared to be in remission.

Sadly, the cancer had travelled to other parts of Anthony's body and, despite high-dose chemotherapy, a stem-cell transplant and radiation therapy, it was not cured.

Through the months of hospital treatment, Anthony and his family were frustrated at being caught between the adult and children's worlds, Jan said.

"There are so many issues that come up for teenagers during treatment, such as how will their fertility and sexuality be affected? Will they be able to embark on study or have any expectation of having a career?"

"What is their life expectancy and quality of life going to be? Can they pass on the cancer to their children?"

"Teenagers are entitled to have their own specialised environment, just as younger children are. They would feel vastly happier if they had access to a space where they could have their own music, movies and games, access to the Internet. posters on the wall, and have friends and family visit in a relaxed environment."

For her PhD research, Jan wants to interview other families who have lived through the experience of teenage cancer.

Contact Jan on 0620 0167 or jan.barling@scu.edu.au
Appendix E: ‘Take 5’ magazine article
My BRAVE boy

Anthony’s illness has made his mum Jan determined to fight for better treatment for teens battling cancer.

My son Anthony was very easygoing, but he was also a deep thinker.

Anthony was in the Scouts and when he was 12, he said: “I think you should be proud to wear the uniform, Mum.”

Ant, as everyone called him, liked what the Scouts stood for – helping others and living by a code.

By the time he was 15, in 2000, Ant was 182cm tall with developing muscles, thanks to bodyboarding.

“He’s my man-child,” I’d tell his dad, Bruce, 53.

People enjoyed having Ant around, and would often comment on how caring and gentle he was.

One of his closest friends was Melanie Charters, a neighbour 16 months older than him. She popped over for a visit on February 15, 2001, and Ant, showing off his muscles, walked around without a shirt.

“What’s that on your back, Ant?” Melanie asked.

It was a firm lump.

“Get it checked out, son,” Bruce said.

X-rays and an ultrasound revealed it was a benign tumour, but Ant had a biopsy just to be safe.

On March 15, five days after Ant’s 16th birthday, we went to see our GP again.

“We’ve found malignant cells in the biopsy,” he revealed. “Ant has a rare muscle cancer called rhabdomyosarcoma.”

But Ant just took it all in his stride.

“I’m not going to die, Mum,” he smiled, thinking he was invincible.

I was a university lecturer in nursing and had been a mental health nurse for over 20 years. Researching Ant’s cancer, I learned it was extremely aggressive.

“If it spreads … that’s it,” I wept to Bruce.

Ant went to Royal Prince Alfred Hospital in Sydney to start chemo in March 2001. He put on a brave face, but I knew he was scared.

“I’m not going to die, am I?” he asked.

“No,” I said, hugging him tightly. He hugged me back, but it wasn’t my man-child.

It was a fragile cuddle from a frightened boy and it broke my heart.

Being 16, Ant was too old for a paediatric ward and was put in an adult ward.

He hated being with lots of old men, just as any teenager would.

Ant liked what the Scouts stood for – helping others.

We weren’t eligible to stay in the Ronald McDonald House because of his age, and unlike paediatric cancer patients, we weren’t even allocated a social worker for support.

“Ant’s fallen between the cracks because he’s a teenager,” I cried to Bruce.

But we took comfort in the fact that he was responding well to the chemo.

“IT appears the tumour is in a specialist said, after Ant’s second treatment in April 2001.

At that time Ant and Melanie from across the road became a couple.

“She’s Anthony’s first love,” I smiled to Bruce.

We were both incredibly happy for them and thought Melanie was great for Ant at this difficult time.

In June 2001 Ant had the lump removed, along with lots of muscle and two ribs, one either side of the tumour in the middle of his back.

Then there was more chemo.

Amazingly, he bounced back quickly.

Even the doctors said he looked too healthy to be sick.

Scans showed the cancer had disappeared and Ant took up bodyboarding again in August 2001.

In November, Melanie and Ant broke up, but they remained close.

A month later, Ant started complaining about terrible pains in his back.

“You’ve probably taken up bodyboarding too soon, darling,” I said.

But scans showed the cancer had returned.

“There are five hot spots on his spine and left knee,” the oncologist said gravely.

“If we treat it all, he’ll be left paralysed.”

There was no cure and the oncologist suggested leaving most of the cancer, only treating the bits that meant Ant could still walk.
That night while Ant was out with friends, I sat in his bedroom howling so loudly with grief that his dog, Mickey, howled too. Ant said, finding me in tears another time. “I’ll sort this out. I’m going to meditate.” That was the man in him, wanting to fix things — and the boy in him that believed it was possible.

Ant started radiation and chemo in December 2001. The radiation burnt his throat and he couldn’t eat.

His weight plunged from 60kg to just over 40kg and he spent a lot of time in different hospitals, always in adult wards.

In one ward there was a man coughing up blood, an elderly man was writing his will and a dementia sufferer tried to get into Ant’s bed. “He doesn’t belong there,” I tried to Bruce. Ant shut down, he wouldn’t even listen to his music. But he still kept on fighting.

By June 2002, when Ant was 17, he was on crutches. The cancer had spread to the bone in his knee. But it didn’t stop Ant, the school’s vice captain, going to his Year 12 farewell, though he needed surgery to rebuild his left knee soon after.

After surgery Ant tried to walk, but was always breathless. “His lungs are full of fluid,” doctors told us, draining off a litre in October 2002. Another litre built up, then another litre-and-a-half, which was tined with blood. Ant was admitted to hospital for a week.

“Ant’s whole left lung is tumour,” his specialist said. But he didn’t stop Ant trying to walk again.

“I’m walking at my formal, Mum,” he vowed. It was on November 26.

But the cancer was spreading quickly, and a tumour had already started developing on his head.

We took him home — to die.

Ant didn’t see it like that though. “I’ve been really sick before. I’m coming back, Mum,” he promised.

He couldn’t make it to the formal, he was bedridden by then.

On November 30, Ant was a lot of pain.

“It’s really killing me, Mum,” he gasped.

“I’ll lie beside you and rub your back,” I said, climbing into bed with him. His sister Melanie, now 27, his brother Glen, 24, and Bruce were there with him, too.

A little while later, Ant gently passed away.

The days and weeks that followed were a blur. I threw myself into work, but nothing took away the pain of losing Ant. A year after he died I took 16 weeks off work, emotionally and physically exhausted.

Returning in January 2005, I planned to start a PhD on stress in mental health nursing. “It doesn’t seem to matter though, after what we’ve been through,” I said to Bruce. And that’s when it came to me. How about studying the experiences of families of teens who’ve died from cancer? I thought.

Still upset that Ant fell through the cracks — he’d ended up being treated at six different hospitals with no real coordination, we believed — I was sure other parents of teenagers had similar experiences.

By then I knew teenage cancer survival rates lagged behind other age groups. With my mental health background, I wondered if it was partly due to lack of support and not fitting in.

I’ve started the study now and I’m looking for family members of teenagers who lost their battle with cancer to help me with my research. Ant would be proud.

“It’s good you’re doing something to help, Mum,” he’d say.

I’m hoping my study will lead to better coordinated care for teenagers like Ant.

That would be a fitting tribute to my gentle soul, my man-child.

Jan Barling, SZ, Alstonville, NSW. If you can help with Jan’s research, please email her at jan.barling@lcca.edu.au or call 0410 599 164.
Appendix F: Covering letter to potential participants
Thank you for showing an interest in my research. As you know I decided to take on this research as a result of Anthony and my own family’s journey with cancer. Anthony was diagnosed in March 2001 and had numerous operations, chemotherapy, radiation therapy and a stem cell transplant. Anthony had just turned 16 when he was diagnosed and was treated in the adult health system in both Sydney and Brisbane. In the various hospitals Anthony received treatment in it became evident to us as a family that there was little support for young people with cancer and their families.

After Anthony’s death, and once the intensity of the grief had subsided a little, I felt I had to do something which may be a legacy for Anthony and others who have experienced a similar journey. After much reflection I decided that I would like, somehow, to influence the care received by this group of people young people who are neither children or fully adult, and are at a stage in life where they are developing their independence. This group of people requires different forms of support than adult cancer patients, given their stage in life and the type of cancers they are likely to have. The majority of young people have aggressive childhood cancers.

During the time Anthony was dying and after his death there was a feeling of isolation, as we knew no other families who were experiencing a similar journey. The support we received was valuable but it related more to the death of an older person, a parent or spouse. Family and friends despite feeling deeply for us found it difficult to help. I decided to enrol in a PhD in order to increase my understanding of these issues. Part of the study involves recording and listening to other people’s stories. I was hoping that other families or members of other families, who have experienced a similar journey, may want to share their stories. I believe that by sharing your experience I will be able to identify issues that may assist young people and their families in the future.

I am an experienced counsellor and I am aware that telling your story will be painful. The reading I have done suggests that simply the act of telling your story can also be a healing experience. I believe I will have an increased understanding of your loss and pain having experienced this myself. I hope that by telling your story you will be able to continue to keep your loved one’s memory alive and help other families cope with the journey that we have travelled.

I have attached an information sheet about the study. If you or another family member wish to tell your story please email or phone me and we will organise a time to meet.
Thank you

Jan
Email jan.barling@scu.edu.au
Ph 66283057
Appendix G: Information Sheet
Information Sheet

Title: From Go to Woe: Families stories of adolescents and young people living with and dying from cancer.

My name is Jan Barling a lecturer in Nursing at Southern Cross University. I am currently undertaking research for my PhD on families who have had an adolescent or young adult member (aged 16-25) who has been diagnosed, treated and died from cancer. The motivation for this study was related to my own experience of caring for my 17 year old son who was treated and died from cancer. This research aims to identify the experiences of family members following the diagnosis, treatment, dying and death of an adolescent or young person. It is hoped that by family members talking about their experience issues may be identified which will improve the care of future adolescents/young people and their families.

The study involves myself asking you, parents and/or siblings to tell your story about what it was like for you and your family caring for your adolescent family member from diagnosis until the final passing and the grieving process that followed. It is thought that it will take about one hour to tell your story, although you may require a follow up interview if you need more time to finish your story. The interview will take place in a private and comfortable environment which has been agreed to by you and myself. The interview will be audio recorded. You will be given a copy of the transcript of your recording and the opportunity to correct/clarify or remove any information that you wish. You may contact me at anytime after the interview if you have any queries.

Your privacy, confidentiality and anonymity will be protected throughout the entire research process. No information given in the interviews will be made public in any form that could identify you, without your permission. False names will be used to protect your identity, as will other identifying places and people. All audio recorded material will be secured by me in a locked drawer. Access to your material will be limited to me, as the researcher, you, as the participant, and my supervisor. This study will be published as a PhD thesis and parts of
the study will be published in relevant journals and presented at conferences. It is probable that members of your family will be able to identify information contained in your story when the study has been published. Due to the sensitive and painful nature of the research topic it is anticipated that telling the story of your loved relative who has died may result in a resurfacing of the emotions you experienced during his or her treatment and passing. You may request to have the audio recording stopped at any time during the interview and only recommence when you feel ready. If you feel you need help to deal with these emotions the names of experienced counsellors, at no cost to you, will be provided to help you cope with these emotions. Participation in this research is entirely voluntary and you are free to leave the study at any time without having to give a reason. If you choose to withdraw from the study your recorded story will be destroyed and the information you have given to me will not be used in the study. If you choose to be a part of the study you will be given a signed copy of the consent form to keep. My research is being conducted under the supervision of Professor Bev Taylor, who is a member of the Southern Cross University’s School of Nursing and Health Care Practices. If any issues or questions are raised as a result of your participation in this research please contact:

Prof Bev Taylor  
Telephone: 02 66203156  
Email: bev.taylor1@scu.edu.au

If you wish to be a participant in this research can you please contact:

Jan Barling PhD Candidate  
School of Nursing and Health Care Practices  
Southern Cross University

Thank you for taking the time to read this information sheet  
Kind regards,  
Jan Barling  
The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee (HREC). The approval number is ECN-05-146
If you have any complaints or reservations about any ethical aspects of your participation in this research, you may contact the HREC through the Ethics Complaints Officer, Ms Suze Kelly (telephone 02 66269139, fax 02 66269145, email: skelly1@scu.adu.au

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome
Appendix H: Consent Form
Consent Form
I ...........................................................................................................
of ...........................................................................................................
..............................................................................................................
..............................................................................................................
hereby consent to be a participant in a study ‘From Go to Woe: Families stories of adolescents and young people living with and dying from cancer being undertaken by Jan Barling as research for her PhD.
The research and my involvement in it has been explained to me and any questions and concerns have all been explained to my satisfaction. I understand that the research involves a recorded interview with Jan Barling where I will tell the story of my and my families experience of my adolescent or young adult family member, living and dying from cancer
I further acknowledge:
□ I voluntarily and freely give my written consent to participate in this research project
□ I am over 18 years of age
□ The aims, methods, anticipated benefits and potential risks of this research have been explained to me
□ I agree to my story being audio recorded
□ I am aware the interview will take approximately one hour but there is the possibility I may require a further interview to finish my story
□ As the research topic may arose feelings of discomfort or distress I may request that the audio recorder be turned off at any time until I feel ready to continue with my story
□ I will be given a typed transcript of the interview in order to make any corrections, changes and/or deletions that I may feel necessary
☐ My name and other identifying information will be changed to protect my anonymity and will not be disclosed without my permission.

☐ I am aware that I am free to withdraw from the study at any time and the audio recording will be destroyed.

☐ I am aware that I can contact a counsellor with expertise in grief and loss if I believe I need further help to cope with some of the painful memories.

☐ I understand the Southern Cross University Ethics Committee has approved this study. The Approval number is (ECN-05-146).

☐ I am aware I can contact the researcher any time after the interview. If I have any further questions about this study I am free to contact Professor Bev Taylor (telephone 02 66203156 email bev.taylor@scu.edu.au).

☐ If I have any complaints or reservations about any ethical aspects of my participation in this research I may contact the Southern Cross University Human Research Ethics Committee through the Ethics Complaints Officer, Ms Suze Kelly (telephone (02) 66269139, fax (02) 66269145, email: skellt1@scu.edu.au. My complaint will be treated in confidence.

Name of participant
Signature of participant

Date
I certify that the terms of the Consent Form have been verbally explained to the participant and that the participant appears to understand the terms prior to signing the form

Signature of witness
Date
Appendix I: Example of analysis transcript with headings
Formed Sectioned story with subheadings of Jenny mother of Brenton Duncan

DEPARTURE

Being told he had three months to live
Brenton was diagnosed in 1998 to begin with, and he was only 12 or 13, with cancer and they told us then, that he had three months to live.

Living two years longer than expected
... but he had 12 months of chemotherapy, then they operated on his muscle in his leg and took the cancer out, and after that he went into remission for 18 months.

Realising he was older and more aware of what was happening to him
Then it came back in the year 2000 and that’s when it was much harder, because Brenton was aware of everything, he was 15 (and so) he knew (what was going on). He had seen children die at the hospital.

Being re-diagnosed with the cancer returning to his leg
...Anyway, we went through having a MRI to find out what had happened and the cancer had come back into his leg and

Not knowing what to do because it was a rare cancer
we didn't know what to do at that stage and neither did the hospital really, because his cancer was one that there was nobody in Australia with and there were only 36 cases in the world. The previous time, when he first had cancer, they gave him a cocktail, they treated it like a Ewing's sarcoma. So, then when he got re-diagnosed we had to work out what we were going to do.

Having to return to the Children’s Hospital as a teenager
...He was in those teenage years, where he was at school, settling in to Year 10 and to be diagnosed with cancer and to have to return back to the Children’s Hospital, where he’d been when he was 12, 13.

Realising he was experiencing lack of contact with other teenagers with cancer
He was getting older and he’d see little children around him, and he didn’t have much contact with other teenagers, because there didn’t seem to be a lot of teenagers diagnosed with cancer there. They were mainly younger children with leukemia and other sorts of cancers, but not a lot that were his age. There was nobody that he could bounce off, telling other children what he is going through or other teenagers. He did get hooked up with Challenge, not CanTeen, (although) CanTeen did once come to talk to him.
EXPLORATION

Having the worst negative reactions to the trialled drug she had ever seen

(The treating) Professor, who we were under, he said: “Okay we have got to try him on a trial, because we don't know what we can do. Are you willing to go on this (drug) through the hospital and we said: “Well, I suppose so.” Well, it was the worst chemotherapy that I have ever seen anybody ever have. He was bleeding from the bottom, bleeding from every part of him, because the actual chemo, it burnt everything and he was sick.

Being nursed in a private room where they do stem cell due to neutropenia
They put him in the back private room where they do the stem cell, because there was nowhere else he could stay. He couldn't be with other little children and there was nowhere really in the hospital. They did have a teenage ward, but not for cancer children - it was only for people that broke their legs, had car accidents and things. They didn't think that Brenton should go into the ward, because he was too sick anyway with his chemo, he was always neutropenic and they worried about germs and things like that.

Staying with him at the hospital for several months
We were in hospital for quite some time. I think it was two to three months and I stayed at McDonald's house.

‘Getting through it’ with her girlfriend
I was his carer and I got through it with my girlfriend. I was a single mum at that stage, my husband and I had broken up the first time round after Brenton had cancer at the end of 1998.

Having relatively unsuccessful microwave therapy
So, then we were at the hospital and we sort of thought what will we do now, because (the) Professor said “that he is probably going to die, because we don't know, we can't do anything about it, we don't know how to fix it.” I had read about the microwave therapy that they have in Perth with (a) Dr and Brenton said when he first got diagnosed in 1998 and there was a girl in the bed next to him who had her leg amputated, Elvina, I think her name was, and they said to her to go to Perth and she did. She had metastases in the lungs and she did this treatment and it cleared up and she is still alive today. She is at uni and everything. Brenton said: “Mum, if Elvina can survive that, can you take me over there?” Well, we had to raise money as it was $5,000 for treatment, so I took him to Perth and we did three weeks of this intense treatment every day and they were pretty good, because they could cater for like his age. I don't know he was accepted into their system pretty well in Perth he didn't mind all that.
Anyway, it didn't work, it did in a way, because he had a metastasis in his shoulder we learned later and that had disappeared when he came back from Perth.
Returning to the Children’s Hospital
And then we came back (after the microwave therapy), we had to come back to the Children’s Hospital, because there was nowhere else to go; we couldn't go to any other hospitals, because there was nothing for teenage children.

Having radiotherapy in the adult health care system with old people and only one other teenage girl
So, then we had to have radiotherapy to keep the cancer under control and we went to Peter MacCallum. Every day we had treatment at Peter MacCallum for I don't know how long it was probably, I can't remember now, but it was all old people. There was only one other girl, she later died, that was a teenager. The two of them would sit there, they were all old men in wheelchairs.

Asking: “Why me?”
... Peter MacCallum were very good because he was young and so they were supportive in that way but sitting there in the waiting room with 80-year-olds I think all the time he was there it was really old people. I mean I myself have had breast cancer and I know when I was having radiotherapy they were older people and I used to think why me. But Brenton at 16 you just thought well this is awful to expose a teenager to life with older people and as I said he thinks why have I, why do I deserve this, because I haven't lived my life yet ... and Brenton would say: “Mum, why me? Why, it's not fair mum, what have I done wrong to get cancer at my age instead of being old? And I'd sort of think it was just awful, you just thought, well, you had no answers. That went on for probably most of the Christmas of 2000/2001.

Waiting for radiation therapy with the old people
That made it very sad, very very sad and I think that the staff there knew that but there was no other facility for them to put him we just had to join in with the old people and wait our turn.

Knowing there was nothing to do while waiting for radiation therapy
They used to bring the vegetable trays around on Friday afternoons and it was like Brenton goes: “Who wants vegetables?”, like being a teenager, the old people all just loved it. There was nothing for him to enjoy, the old people had bits and pieces that they would do with the people there, but nothing for Brenton as a teenager, no that was hard.

Pulling away from the hospital to find other solutions
Then we pulled away from the hospital, and pulled away from everywhere, because I was trying to look up everything, how I could get it all fixed, or what we could do.

Returning to the Children’s Hospital for more chemo which was stopped due to complications
We had to end up going back to the Children's Hospital, and having more chemo. But then he started to bleed from the kidneys and he couldn't have any more chemo.
Having his leg amputated
Then, they said, “well, we will amputate his leg”, because they did a test and there was no metastasis at this time, because I think the treatment in Perth had cured any metastasis, I think that’s good for things like that but not the big tumour he had behind his leg growing again.

Returning to the Children’s Hospital as a ‘full on’ teenager
Anyway, so we went back to the Children's Hospital, and by this time he was shaving. He was a real full on teenager, like he was having sex at that stage with his girlfriend, because I knew he might die. I let him do things I might not have normally but do things like a normal teenager would do. But then he had to go back to the Children's Hospital, and like lay in the bed with all little kids around him. It was undignified in a way because it wasn't fair what he had to go through, and he couldn't be a person in his own right.

Appreciating that the Children’s Hospital made adjustments for a teenager
So, we used to take his friends in and we had our own room there. We asked for our own room and all his teenage friends would be there and they’d have bits of, not parties, but they would try and cheer him up all the time. And they let Jade sleep in the room, that’s his girlfriend, at night, but it was really bad, because it was a Children's Hospital. The nurses just loved Brenton so they were very good about that.

Describing his optimism for life after the amputation
So, then he had his leg amputated, and after that he came home, he said to me: “Mum, I'm free of cancer now, I'm going to get married one day, I'm going to be the best one legged golfer”, because he loves golf, and he said: “I'm going to, it's going to be really good, life’s going to be good”. And I said: “Yes love, we are going to really move on now”.

Failing to recover after the amputation
Well seven weeks later, he is not feeling well, sleeping a lot, he didn't really tell me that he wasn't feeling well. But I could tell that he wasn't picking up, like he should have after having his leg off. I said to the hospital: “Well, shouldn't he be better now, like not better, but shouldn't he be feeling better, I know it's a major operation to have your leg off, but he is very tired and is not feeling very well”, and they said: “Well, come in for tests”.

Being told the cancer had spread
So we went back and he had tests, CT scan ... and as soon as they put him in the room the radiologist called me over, that's right, his groin was really painful, and he had the CT scan, and they showed me that there was a big tumour in his groin, and it was in his pancreas, it was in his lung it had just gone everywhere. They had only told me though that it was in his groin there at the hospital.
Being an AYA in children’s cancer ward
... (When he got the metastases) he was the oldest in the ward and you just felt for him, because there was nobody like his age or to talk to him like a teenager ... It was difficult, because there were young children around everywhere in the hospital and he was virtually a man, because he was shaving, he was a grown-up, he was tall, he was nearly 6 foot in height when he died, so it wasn't like he was just a kid ... He was ready to start work, he had part-time work when he was rediagnosed in 2000 and like, here we are with little kids, who have never known what the world is like, so that was very difficult, ... but because he'd been through the Children's Hospital we couldn't really go anywhere else, because they had the history.

Not being able to sleep when dying in the Children’s Hospital
... Some nights Brenton couldn't get to sleep, because in the ward there were babies crying and I mean what sort of life is that for a teenager that is dying of cancer, to have children crying in the night. They were sort of the hard things that Brenton faced.

Realising there were no facilities for teenagers with cancer in hospitals
But I don't think there were the facilities for teenagers. I think it would be great if they could have some sort of support system or a ward just for teenagers with cancer, instead of mixing them up with all the young babies, the two-year-olds. ... When we were going through the radiotherapy at Peter MacCallum that was really difficult to as I said because they were old people. They do need some sort of teenagers with cancer facility like all the way through, for the radiotherapy, for the chemo, for the wards. But I mean, let's hope there are not that many children or teenagers with cancer, but they need to have some sort of set up for that age group, because they don't fit in as a child, and they don't fit in as an older person.

Finding it difficult to be the ‘sounding board’ for intimate details
Also to, like sexuality there was nobody for him to talk to. I mean, he used me as his sounding board for practically everything. I think we grew so close, about dying, he talked to me, and he didn't talk to a psychologist or anybody like that. He talked to me about his fears, the way he felt, and all about like his sex life, I knew everything about him, because he talked to me and told me, he had no one else really to talk to. I mean he had his friends, but he wasn't going to tell his innermost secrets and things to his friends. So, that is where I found it really difficult and so did Brenton.

DESTINATION

Being rang at work to be told he was going to die
Then we went home, and the doctor rang me at work and said to me: “I'm sorry, but Brenton is going to die, we can't do anything about it. He has got metastasis everywhere”.

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Telling him what she thought he already knew, that he was going to die
… so, I just came home from work and we didn't know how to tell him, but I think he knew anyway. He was down at his girlfriend's place. We said to him that night, we said: “Brenny, its comeback, you've got metastasis”, and he said: “Yeah I'm going to die, aren't I mum”. I said: “Yes love, you are”.

Reassuring his mother that he would be okay
And he cried. Then he said: “Mum, I'm going to be okay don't you worry about me”.

Continuing his relationship with his girlfriend
Anyway, he went on going down to his girlfriend's place, he was not well, but he wasn't sick sick.

Giving up work to be with him
I gave work up while this was happening, because I didn't know how long he was going to have left. This was August and he died in the October.

Experiencing he needed morphine for sudden, severe, acute pain
… and I was going shopping one day and my oldest son Alan said to me “mum Brenton has just rung me and he is in absolute agony down at Jade's place”. He said “I will pick you up and we will go down there”. Anyway, we went down and he was lying on the floor and he said “nobody come near me I just need something to knock me out I'm in so much pain”. It came on him really quickly because that morning Jade said “he was fine like he hadn’t complained about being like this”. Anyway, he was screaming in agony and we got the district nurse to come around and give him morphine.

Putting him to bed at home for continuous morphine
He had been on morphine but only liquid morphine and they put a driver into him and then they brought him back to my house and we put him to bed and we will be able to look after him in bed.

Acknowledging he would have nothing to do the palliative care team
But then the paediatric palliative care people came down from the Children's Hospital and said to us “well this is what to expect now”. They wanted to talk to Brenton but Brenton didn't want to have a bar of them, and he was actually awful to the guy, because Brenton said “he chatted up all the women”, the paediatric guy that was in charge of everybody chatted up all the mums, anyway I think he got the sack in the end. He was terrible.

Getting no support from the Children’s Hospital when he was dying at home
… so we never had very good support through the Children's Hospital when he was dying. I asked could he be admitted there when I couldn't cope for a night and day. They really wiped their hands of us, we only want children that we can cure or we can help but he is dying so no … But it just was difficult with him and having no support from the Children's Hospital. One night I was
really in crisis we got an ambulance to the Children's Hospital and they were very very like “why are you here we can't do anything for him”. I said “where else can he go?” And there were no answers.

**Realising the hospice was unsuitable for an AYA**

… They did offer the hospice around the corner here but I went around to see it and it was just full of old people and I couldn't put my son there.

**Feeling unsupported in giving care**

I know he wanted to die at home, I mean it was just to give me a bit of relief because I was doing it all by myself or with my girlfriend and it was really hard. There was no support there for anybody really to come and talk to Brenton. I would have liked somebody to be his age or a nurse that would be on standby all the time.

**Having no continuous support person**

We had the district nurses come in and give him his morphine and go again and they were all different, except one Maxine she was fairly good but there wasn't the same constant person that Brenton could look up to or talk to coming round.

**Talking to the hospital about lack of support**

… I talked to the hospital about this (lack of respite and support) because I would have liked them to provide - if they can't have him at the hospital, provide a nurse to be there, that he has known through his time at the hospital. A nurse to come and be with him at our place and I said “I would have even paid for her to be with me,” but he had none of that.

**Feeling concerned about having complete control of his morphine**

… It was hard to have complete control over your own son. I was even putting the morphine needles into his (cannula) when he wanted morphine. They said to me “you just do as you see fit”, and it was like I could have killed him, and how would I feel if I overdosed him on morphine? But they let us have complete control because there was nobody else there to look after him.

**Needing structured organised help**

… It was an awful time because it was just so higgledy-piggledy, there was nothing in place like, I’d ring the Children's Hospital and they’d say “we'll put you on to the pain relief people”. And you think well okay but this is not what I need. I needed to have somebody to help out with everything but there wasn’t that help.

**Hearing him asking to die**

My GP Dr. Brenton begged him “look” he said “if I was a dog you would give me a needle and put me down”, he said “I'm in agony here and I can't do anything about it please let me die tonight”. The doctor said “no we can't do that”.

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Looking after him as he deteriorated
Anyway, it went on for him and then he started trying to get up a lot because of the drugs, he got out of bed and he was falling over things. We had to shave him, and he just couldn't do things for himself any more and he drank out of a baby's bottle in the end because he couldn't feed himself because he was so sick.

Being able to have conversations with him towards the end
And then probably, the last two weeks he just lay in the bed but he could talk he was okay to talk and he had cut back the morphine. For some reason they put him on hypnovel which seemed to work. He was on a lot of morphine at the end but he felt he could still have conversations with me, which was nice at the end.

Enduring hard work so he could die at home
And he wanted to die at home so I wanted him to be with me but I just needed a respite every so often because it was very hard work when you don't know how long it is going to take, it's just all really really hard.

Realising he was making life easier for others
… He made his death easy for me because it was never poor him, he always gave out to everybody else and he’d say “how are you?” One night when his girlfriend was there and it was two or three in the morning he said “Chris you're not still here, oh you poor thing you will be so tired in the morning” and she said “but Brenton you’re dying I won't ever have this time with you again.” He said “oh but Chris I worry about you,” he was just so giving.

Watching him thank the doctor, who later cried with respect for him
The Professor his doctor, said “when he told him about his metastasis and that you’re dying,” he said “most teenagers would hit the pillow and say f this, f that, why me, it's not fair but Brenton just shook his hand and said thank you Professor for giving me all the love and care that you gave me.” And (the) Professor had tears in his eyes and he went out to the nurse’s station and he just broke down and said “that child is a true gentleman” he said “I've never had a child like him he said he's been a wonder to look after.”

Asking whether he would die that day
…The District Nurses were coming every 4 hours even in the night and he started getting the death rattle that morning and I said to them “is that the death rattles?” and they said “with Brenton he could go on for another week the way he is because his heart’s so strong, even though he’s sick he could go on for another week” and I said “I thought may be today because he’s got the death rattle and they said no.”

Keeping a care roster in the last couple days
… We did a roster the last couple of days because I was getting burnt out and just couldn’t keep going for 24 hours, so what we did is we all took turns. It
was getting too much with Jade his girlfriends family because they were coming a lot to visit and I just said “we can’t do this we have got to do this in shifts so we drew up a plan.” – Bec my daughter-in-law did this, we drew up a plan that said like you can have this hour.

**Brenton’s girlfriend swapping a shift the day he died**
That morning Jade rang and said “is it alright if I swap my afternoon to the morning?” And I said “well if you want to I didn’t ask her why.”

**Being there the day he died**
… The day he died Chris, my girlfriend, my future daughter-in-law Bec, she’s a registered nurse, she was off for the day and Todd (Brenton’s brother) asked me that day if he could stay home from school, he was only 13 at the time and I thought oh well yes, but we didn’t know that Brenton would die that day.
… Anyway, we were all there and I was washing the dishes and Chris said “I think we should turn him because of bed sores.”

**Dying in his mothers’ arms**
And we said “Brenny we are just going to turn you,” and we turned him and he was groaning and I was there cuddling him and that is when he all of a sudden sat up and reached up while I was cuddling him, and then he laid back down and died in my arms and it was the best – I mean it was just lovely that he died in my arms. I was so lucky, not lucky, you know what I mean.

**Reflecting on lack of support**
… Anyway he died on the 12th of October around lunchtime and after he died, when I look back now you just think well there wasn't a lot of support at all for teenagers with cancer.

**Feeling a sense of relief**
the day he died in one way it was a bit of a relief because of having to look after such a sick child who was saying “please God take me tonight.”

**Knowing he was going home when he died**
I mean he was such a Christian it was easy in one way because he said “I am going home mum, I'm going home.” As I said to you, before he died he reached out to the corner of the room and was trying to tell me “mum, mum, they’re here” and then he just lay down and died. That gave me a lot of comfort afterwards because he wasn't scared of dying, he wanted to die in the end.
Appendix J: Core Stories
Cameron’s story: Brother of Kristie

Departure
I remember the family noticing a lump on the side of Kristie’s left hand, which we thought would go away. The lump started small and then it started to grow. Our family went to five doctors who all said the same thing - it was just a lump or a cyst and it would go away. Eventually, my Mum took Kristie to the hospital and said there is something seriously wrong and got her some tests and they found out it was rhabdomyosarcoma. I remember the doctor saying that she had a primary and a secondary tumour under her arm, which wasn’t a good sign. My first thought was, ‘Jesus we’ve got this problem’, but now I realise that at 14 I didn’t have a good grasp of what was going on. I just accepted what was going on and went with it.

Exploration
I recall Kristie having immediate chemotherapy and once the tumour went down they cut out the tumour and the finger bone. Kristie then had 12 months of chemotherapy, three weeks on and one week off. The tumour underneath her arm went down so they cut that out also. The first year was intense and I watched her go from being healthy to very, very ill. Some of the challenges of being a teenager having treatment were the loss of hair, not being around friends, not being part of the fun of high school. Kristie used to wear wigs so it looked like she had hair but she decided to give that up two years into treatment; she said, “Bugger it, this is who I am and this is what I’ve got.”

After the treatment Kristie then had regular checkups and scans for eight months and then the doctor noticed a lump on her right buttock. The cancer had come back but it wasn’t as bad as last time. Kristie had chemotherapy again and radium to reduce the tumour, then they took it out.

It was very hard for Kristie, a person 13 going on 14, it was very stressful and painful. She was a tough little girl who matured very quickly and missed her teenage years and went straight to being an adult. Kristie went to school any time she had free, even when she was sick, just to be normal. She was a teenager and didn’t want to be in hospital.
Chemotherapy placed a large burden on the family. It was a two hour drive to get to treatment then another two hours of chemotherapy and then back home again, so we were pretty much there all day. My father had to work to keep an income coming in and my mother gave up work to be with Kristie. During those two years I would give Kristie support and muck around with her. I was going through the motions of my life and understood that this was a problem that we would fix together. I believed that cancer had become a part of the family and I realise I didn’t see it as a big thing and I didn’t understand the ramifications.

Kristie and I were going to get through this together as a team, I was the big brother and I wanted to look after her and be there. I went to the hospital with Kristie, and made sure of that. You just got in and did what you had to do; the doctors said this is what you have to do, so you do it. I watched her in pain and not being able to help with the pain; I would try and divert the pain by clowning around.

After the surgery on her bottom we went for a holiday overseas to Disneyland. I remember her complaining about cramps in her shoulder blade and over the next three days the pain became worse and so we expected the worse.

**Destination**

It was devastating watching Kristie, who was going through this expecting the worst, and then getting the test results and finding out it was in her lung and it didn’t look like chemotherapy could do the job any more. It was horrible just thinking about it, let alone being the person who has to go through all this treatment again. It was an emotional roller coaster, hitting rock bottom again and starting chemotherapy again. I believe I was in denial until she passed away. I was thinking the chemotherapy and the medications would take care of it.

I went on Schoolies with her the month before she died, just to have fun. We had a great week together with her and her friends and it was almost like a goodbye. After that she couldn’t do anything or go anywhere because she needed oxygen. Kristie never let on that she was struggling with the tumour and it wasn’t until two weeks before she passed away that she let on. I remember pushing her up the top of the stairs and her saying, “Cameron I really love you.” I knew then that she knew that she was not going to make it.

The way Kristie passed away was such a cruel thing for a teenager to go through. She had to go on oxygen to breathe and she couldn’t talk because she had to concentrate on the
breathing. I felt a sense of relief when she passed, a sense of freedom for her. I hoped it was easier for her in the afterlife, because it had been a tough run here.
Irene’s story:  Grandmother of Thomas

Departure
It all started with Thomas complaining about a pain in his knee. I asked his mother to take him to the doctor. When they returned she said the doctor had decided to get some x-rays and he would ring if there were any problems. The phone rang about an hour later and the doctor asked to speak to Thomas’ mother saying it was pretty urgent. After the phone call, Thomas and his Mum went straight to the doctor. When they came back, about an hour later, Thomas had such a look on his face as if he couldn’t figure out what was going on and his mother looked absolutely drained. I asked what was the matter and his Mum said, “He’s got a tumour in the back of his knee.” I asked, “What does that mean?” She said, “A tumour is cancer.”

Exploration
Within two days Thomas was in hospital - I spent a lot of time in hospital with him. Sometimes I would sleep overnight so I could be with Thomas. It was hard to watch him so sick with the chemotherapy.

I remember the lack of privacy Thomas experienced in hospital; he was in a ward with six others. He used to get embarrassed when everyone in the ward could hear him weeing into the water bottle (urinal) and how, when he was sick in one of the bowls, everyone would look. There was a baby that was screaming day and night. Thomas was bored because he wasn’t the type of kid to stay in bed all the time. One of the hardest things I experienced was watching children suffer and die around him. Thomas just couldn’t wait to get out of there. I knew that although it was terrible there was nothing I could do about it because he had to be there when he was sick, we couldn’t take him home. I appreciated the fact that he was getting the finest treatment.

The hospital was accommodating and when he was sick from the chemotherapy, he might start feeling better at about 10pm. Thomas would ring me and his Grandfather, up at the wood fire pizza shop we owned, and ask us to bring a pizza to the hospital. We would stay with him until about 2 am and the hospital didn’t mind.

One nurse, in particular, developed a relationship with Thomas and made his stay in hospital easier. The nurse was an Arsenal supporter and Thomas was a Manchester United supporter and they used to have some friendly fights between them about whose team was the best.
Thomas had a Manchester United flag behind his bed and the nurse would try to take it down and put an Arsenal flag up. The nurse came to the funeral with his Arsenal shirt on; “This is just to put the shits up him,” he said.

After x-rays and an MRI the doctors seemed to be happy about the way things were going with the chemotherapy. Because it was bone cancer it was hard for the chemotherapy on its own and it was only holding the cancer back, so the doctors decided to try radiation therapy as well. The radiation on Thomas’ leg looked as though someone had set it on fire and all his hair started falling out with the chemotherapy. I was told by Thomas not to cry but I couldn’t help it. When he saw me with red eyes he would ask if I’d been crying again. Thomas would tell me not to cry and that he was going to be all right, and that I was not to worry about him as he would be fine.

After the chemotherapy and radiation therapy life was good for nine months. Then the cancer reoccurred and the doctor decided the best way to go was to have Thomas’ leg off. The doctor hated telling Thomas because he knew how much Thomas liked playing soccer. He had an above knee amputation to make sure they got it all.

Thomas was amazing just after the amputation. An hour after Thomas came out of the anaesthetic he was on his mobile phone to me, he took a picture with his mobile phone and told me to look and see him with his leg off. I couldn’t believe how amazing he was. Thomas and another patient his age, who’d had an amputation from the hip down, used to run around the hospital like lunatics on their crutches. The nurses used to be in stitches. He coped with the amputation very well.

I was amazed at the things he could do, bowling, playing cricket, kicking the football with his one leg, go into thin air, and come back down on his one leg. One day when he was kicking the ball it went over the wall, I remember him climbing the wall with his one leg, hopping over the other side, shooting the ball back and climbing back over. Another time, not long after his amputation, I asked him if he wanted a swim in the pool. I thought he couldn’t swim on one leg. “Don’t worry I bought you a pair of flippers,” my husband said. He brought out two pairs of flippers. “Grampy I don’t need the two, only one,” replied Thomas. He put a flipper on one leg and went into the pool. I had never seen anyone swim so fast. They couldn’t get him out of the pool after that, he just loved it.
I thought he was just bloody amazing. I marvelled at how strong Thomas was and that despite everything he was going through, we never ever heard him complain. When I saw him doing things like that I didn’t realise he was going to die. I probably did, but I pushed it to the back of my mind.

After Thomas learned to walk with the crutches, he started to walk on a false leg, but he didn’t like the false leg as it was uncomfortable. We tried to raise money for a proper artificial leg that looked like a leg, but we were told we were wasting our money, as he would outgrow it and we’d have to buy another one.

Destination
After Thomas had been through all that, the cancer metastasised into his lung and he had to have two lung operations. They removed 10 tumours from one lung and 12 from the other. He had more scans and everything looked fine.

Thomas had expressed a wish with the Make a Wish Foundation to visit Manchester United the following year. The treating team had requested that the wish be brought forward. I could see what was happening. I had always thought that the Make a Wish Foundation was for someone who was going to die; the treating Team assured us it was not for that, it was for children who were going through a lot of pain. I asked his mother why they had brought the trip forward and his mother said “They don’t think Thomas will be here for next year.” He went to Manchester in May that year and at the end of October the treating Team said there was nothing more they could do.

It was terrible to see Thomas on the wards. He hated hospital so he asked to go home. He didn’t want to be in hospital for the ‘last.’ He wanted to be in his own bed and do his own thing. To make this possible we had a doctor who used to call in every morning and evening to check on him. There were times when his mother would ring at 2 or 3am asking if we could look after his sister as Thomas was having trouble breathing. He would go into hospital for a couple of days and then come home.

Being at home was easier, because you could just pop in any time and sit beside the bed and talk to him. Hospitals had their restrictions and you had to consider the other patients. If any kid is going through what Thomas went through I think it is better to be at home rather than in hospital.
We tried to make things as good as we could for him. Thomas’ friends would come on the weekend and there were mattresses all over the floor, they would watch silly movies and have a few soft drinks. We bought him a bar fridge to keep next to his bed, so he didn’t have to struggle out of bed and we moved his bedroom so he had an ensuite.

I remember how funny Thomas was on his Mother’s birthday. He had a few bourbons and coke; there was nothing else, so we let him have a few bourbons and coke. After that every time I came to visit he was always in bed. His mother told me he was really sick.

Prior to him being really sick Thomas asked me to buy some tickets to an Oasis concert, his favourite band. He was too sick to go when the concert was on and I knew he was really sick then because he would not have missed the concert for the world. His friends went to the concert and held their mobiles up so he could listen.

I could see Thomas start to ‘go downhill’. He looked a bit grey and he lost his healthy appetite. He used to eat steak until the cows came home, but in the last three weeks a yoghurt was as much as we could get down him. During this time I remember my son (Thomas’ uncle) telling me not to block it out of my mind that he was dying.

My son (Thomas’ uncle) bought him a big, huge scale electric racing track as an early Christmas present. We played with it for hours and hours. Every time I accelerated around the corners the car came off the track and Thomas went into hysterics and told me, “Nana you’re always bloody dizzy you are, take it slow around the corners and then go faster.” I looked at him then and saw he was ‘going downhill.’ After playing with the electric racing track he went to bed and I don’t think he got out of bed again.

I remember the doctor saying that if Thomas passes away in the night to keep him as long as we wanted. He didn’t pass away in the night and the doctors were coming in and out; they connected him to this big breathing machine and were giving him morphine. He was off his head with the morphine but he was still happy and he knew we were there. It was dreadful watching him suffer day after day.

The day he died I went home to change my clothes. “Don’t be long,” he said. “I won’t be long,” I replied. When I went back in the afternoon his other grandma was crying. She told me it
looked like he was going. I asked to see him, but his mother and father wanted to be with him on their own. All of a sudden I heard this music go on, it sounded like Oasis, I heard his mother scream and I knew then that he was gone.

It was peculiar actually, he just passed away, and that was it. I had to wait a few minutes to see him. When I did see Thomas I laid by his side and kissed him; I was so sad because he’d gone and I never said goodbye. We dressed him in his shorts and his Manchester United shirt.

His school mates were amazing; they had never seen or touched a dead body before but they helped lift him off the bed onto the Undertaker’s trolley. I gave him a kiss before he went. Thomas used to hate me kissing him because I would leave a lipstick mark. He used to rub his head to try and get it off and told me to stop doing that. After I gave him the kiss I said, “Sorry Thomas,” and rubbed it off. When he left I asked the undertakers to look after him because he had been through enough. They said they would.

I just couldn’t believe it at the viewing, seeing him in a box, dressed in all his Manchester United clothes with letters in his hand from all his friends and photographs. I encouraged his sister to see him, she was terrified because Thomas was dead. She (his sister) saw him, kissed him, and couldn’t believe how cold he was.
Mike’s story: Grandfather of Thomas

Departure
I recall Thomas going to the doctor with his mother because he had been whinging about a little pain in his knee for weeks. When they returned I remember his mother crying her eyes out and saying he had a tumour on his knee. I looked at the X-ray and it read osteosarcoma and I knew it was about bones.

Exploration
When Thomas first started chemotherapy I didn’t realise how bad it was and thought - he’ll get over it. For the first few weeks of treatment I was numb. You’re asking people the hospital procedure and then all of a sudden you realise you are climbing a ladder. Thomas found it hard at the hospital, he was locked in there with babies crying and when he had his leg off he was in the ward with older people. I thought - this is a bad journey.

When Thomas had the amputation I realised things were a lot more serious. After the two lung operations Thomas became really well and you wouldn’t have thought there was anything wrong with him. He seemed well when he went away, through the Make a Wish Foundation, to meet the players of Manchester United and to tour London.

I was told at the hospital to be prepared for it and that I might need counselling, but I felt I didn’t need it being a man. The one thing I did find hard was losing all my friends. Even members of my wife’s family didn’t keep in touch.

Destination
I knew that Thomas was going to die after I made an appointment with my doctor. I showed my doctor a copy of the form that the family had taken to London in case anything went wrong. My doctor told me straight, he said he would be lucky to make his birthday and that there was no chance he would make Christmas. I never told my wife (Irene) because I knew she would be a complete mess; I just bottled it up inside. I knew it was coming and when it came it was hard. Thomas didn’t suffer for long, probably only two weeks. He stopped eating and really started losing weight. It was awful to see a young man slip away like that.
Josephine’s story: Mother of Christopher

Jo started telling her story by showing me a photo of Christopher on the wall, which had a poem near it. Jo recited the poem, which was about Christopher being safe with Jesus after his death. Jo said she found the poem comforting and used to read it when she could not speak. Jo felt that, to tell the story, it would be easier for her to use the photo albums she had put together of Christopher’s journey. Each photo triggered a memory for her and his experience through the cancer journey.

Departure

I thought something was wrong when Christopher started complaining that his leg hurt and later that day he said he was cold and he was shivering. I took his temperature and it was 39.6°C so I knew he was sick and I had to get him to hospital. When we arrived at the hospital we sat there waiting to be seen. His leg was swollen by this stage. He was seen by the surgical registrar who referred him to the medical registrar, who wanted to refer him to the surgical director. I remember not being believed that his leg was swollen and that he needed antibiotics, but he had a galloping heart murmur and a temperature so they admitted him. A couple of days later I looked at some plain X-rays they had taken, which I thought looked a bit funny but I didn’t want to know. I was told by the Cardiologist, under whom Christopher had been admitted, that the X-ray showed something sinister and they would do a CT scan. After the CT scan we were told it was Ewing’s sarcoma and that Christopher would have his leg amputated at the hip. We would have to move to Sydney for treatment and he would have to use crutches from now on, because he would get a fracture if he fell over. The tumour was huge, two thirds of his femur. The way we were told of the diagnosis was not a good way to do it. Christopher was teary, I was stunned and his father just sat there.

The place where he was diagnosed in Sydney was a horrible place. It had little metal bedside stands and curtains you could see straight through. I had a bit of hope when the Professor said that Ewing’s can’t be diagnosed with X-rays and they would need to do a biopsy to confirm the diagnosis. I remember waiting in a huge waiting room full of people for Christopher to be admitted to hospital. When he was admitted to the tumour ward the ward was like a ward from ‘Carry on Doctors’ with rows and rows of beds and vinyl floors and full of old men.

The biopsy confirmed that it was Ewing’s sarcoma and my hope was now gone. Christopher had another biopsy of lesions on his lungs, but they were lymph nodes in the wrong place. We
were given the choice of him being treated in the adult or children’s system. We chose the children’s system because of his age and the experience he and we had had with old men in the ward he was in at present.

**Exploration**

We returned to Sydney for treatment, which was difficult. Christopher was put into a room with a five-year-old girl with a similar surname, because they thought they would be less likely to mix up the drugs. At the Children’s Hospital they expected a parent to remain with the child 24 hours a day. At night we had to push the kids’ beds together to fit the fold-up beds in the room and then there was only room for the IV poles.

I didn’t know what to expect when Christopher’s central line was put in and I felt at a loss when he was having chemotherapy. I felt unprepared for the side effects of chemotherapy. I went to a parent’s support group and told them that I didn’t know what to do with the mouth ulcers he had developed after the chemotherapy. The medicine and the mouth wash that the hospital had given me, was not working and he was in so much pain. The support group advised me to ring the hospital ward and they would give me some Xylocaine gel. I rang the hospital and they told me to come and collect it, but I didn’t have a car so a friend collected the gel for me. He was a really kind man. Christopher ended up with ulcers right through to his anus, which was horrible and nothing prepares you for it. I learnt more from the other parents about what to do than I did from the doctors.

After the first lot of chemotherapy and after reading the information I had been given, I knew I would have to go back to the Sydney hospital for scans in three months time. I remember Christopher having the scans and the comedy of errors that occurred, such as the hostel not being booked and X-rays not being sent up. This always seemed to be happening with his admissions.

After the scans I rang the Sydney specialist to see where we should go after the scans. I was told by the specialist that Christopher would have to come to the Sydney for radiotherapy for seven weeks. I knew that as a single mother it was impossible to move to Sydney for seven weeks; as a family we didn’t have the money and we had nowhere to stay. I spoke to Christopher’s paediatrician, who was pretty fantastic, and who arranged for Christopher to have the radiation therapy in the local hospital. Christopher was the first child and the first ‘leg’ that they did radiation therapy on in the local hospital.
There were really old people in radiotherapy. I remember one old man telling Christopher what an inspiration he was. The radiotherapy staff said Christopher never shut up when he was having radiation therapy. On his 14th birthday the Radiation Department made a special effort with decorations and taking up a collection for him. When he returned home a famous rugby league footballer visited and gave him his grand final jumper. Then his friends came for cake and lunch. He was really excited.

The next day Christopher had chemotherapy. He missed one cycle because his white cells were low. The doctor in Sydney had wanted him to have the cycle. I realised that I had had no contact with his oncologist in the Sydney hospital since his initial chemotherapy. I thought this was not right, as other parents had contact with their specialist who would visit from another Sydney hospital. I also realised that Christopher was not receiving GPFS, which the other patients were receiving. I asked my specialist if Christopher could have the drug and the specialist said the drug was too expensive. I then spoke to a local paediatrician requesting that Christopher be treated by the hospital that had the visiting specialist. I told them that I wanted Christopher to have the GPSF and it was done.

When I met the visiting specialist I did not like him very much. He was rude about the bruising around Christopher’s umbilical area from the GPSF. When Christopher had a fall and fractured his femur, I rang the specialist to let him know and he said, “What type of nurse are you if you can’t describe where the fracture is?” I said I was confused, tired, and stressed and couldn’t think straight and my nursing training was much different to what it was now.

Some of the experiences in the hospital, such as a teacher from his school organising the kids to come and visit him once a week, the opening of the quiet room on Daffodil Day and painting daffodil tattoos on him, are positive things I remember. Christopher was happy in hospital playing Nintendo. He was a happy boy despite the cancer; he had the most gorgeous smile and he just never complained about it, he never wished it to happen to anyone else. I recall Christopher painting a picture of what hospital meant to him. He painted a battle scene. People looked at it and were a bit embarrassed, I said to them, “Isn’t he fighting a battle?”

Christopher was so skinny, with the cancer eating away at him, although it was still physically difficult lifting him in and out of the wheelchair. I had some supportive friends who were wonderful and took him overnight. I supported another mother, whose daughter died in the hospital ward, by staying with her until the Funeral Directors came to pick up the body. I was
happy to help the nurses out with Christopher’s care because the nurses were just so overworked.

Anticipation

When Christopher finished treatment he was given a certificate and they had a cake for him. Christopher and the nurses had a water fight with a super soaker and a 20 ml syringe that destroyed the cake. It was weird. After the treatment he spent a week at his Grandparents’ farm, it was the first time he’d been since his treatment. He was on crutches after treatment and then he started walking with sticks. His hair was growing back and he was unhappy about it because it was curly at the back. When he was at the farm I painted his room to look like a castle and when he came home his jaw just dropped, he was so excited to be in this room. I thought at this time he was getting sick again.

I took Christopher to the clinic, and was told that mothers always worry afterwards and that he was fine. I thought he was still sick. I finally decided to ring the Sydney oncologist for advice about what to do because he was lethargic and sick again and I was really worried. The oncologist suggested he would probably do a bone marrow aspirate. So, we went to the hospital and told the paediatrician what the oncologist had said to do. I got better at advocating for him as time went on. The bone marrow aspirate was the worst thing they had done to him and it was a nasty experience. A medical student rushed out throwing up and it sounded like fingernails on a blackboard. It was just awful and very painful for him.

I remember ringing the doctor’s rooms and being asked to get to there as soon as possible. I had to negotiate borrowing a car to get to the rooms. When I got to the rooms the paediatrician acknowledged that mothers’ have a good instinct and that doctors should listen to mothers more often and that Christopher was relapsing with Ewing’s in his bone marrow.

We went to the Sydney hospital to start the Ewing’s relapse protocol but they had to stop it because of acute myopathy. Christopher was sent home and became really sick with the chemo he had, and he was admitted into hospital. I found out, after he died, that the treating team didn’t really know what he had. During this time the generosity of people lending their cars is something I recall. At one stage I had a car continuously for quite a few months.

I can remember an attempt at a painful examination, with both me and the doctor crying and the doctor deciding to airlift Christopher to Sydney so the examination could be done under

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general anaesthetic. When we arrived at the hospital after the airlift, the morphine had worn off and I demanded he be given some more. Christopher was admitted into a six bed ward and they were trying to barrier nurse him. They eventually put him in the bone marrow transplant bay, which smelt like a wet dog.

When Christopher started to pick up we had a day trip to the zoo but it became clear he was sick and he had to return to the hospital. He was in hospital for 10 weeks. I slept on a fold-up bed in the patient’s lounge because he was too sick for me to sleep at the Ronald McDonald House. Christopher refused to have me sleep by his bed. One night he got really sick and he did not want to wake me so another mother cared for him. I felt bad but the mother said not to worry because it was what Christopher wanted. This mother and I both tried to share the load when we needed a break. I remember coming home after ten weeks. Christopher spent most of his remaining time in hospital.

I have many photos of the Camp Quality camps and activities Christopher experienced. One of the most exciting activities was a balloon flight and I was told I had to go with him. It was the best thing I had ever done, it was fantastic.

Destination

We went to Sydney for the bone marrow staging, where he had all these tests. After this I was asked to go to the doctor’s rooms and I was told Christopher had relapsed and there was nothing more they could do. I know he knew he was dying by the look on his face when they went to tell him. He cried and said, “Why me?” then in the next breath he said, “Why not me? I can’t wish this on any one else.” There were never any tears again. He insisted that I go to see Phantom of the Opera and have dinner with a friend the next night and that I have a good time. When we got home he asked me to ring the Funeral Directors so he could get that out of the way and then have some fun. He was in and out of the ward every week for blood transfusions during this time.

The last Christmas we had together we had early because Christopher had been due to have a bone transplant at Christmas time. I remember him swimming in the pool and the plug coming off his catheter. I rang the hospital to see what to do and they suggested flushing and doing a head block. I did so, he was having such a ball in the pool and we knew he was dying so we thought, go for it. He got really sick that afternoon and had to be taken to hospital.
He was tired on his last Camp Quality camp. I tried not to be too concerned about the camp even though he was on death row. He had a good time. At the camp he wanted to dress up as a skeleton at the Fancy Dress party, because he would never be one after he died. He had decided to be cremated.

It was Christopher’s wish to be cremated and I had to convince an aunt it was his wish because the aunt was concerned he would not come back at the second coming. I later discovered he told this aunt that he wanted to be cremated, because he wanted to destroy the body that had let him down.

He had a black sense of humour and I recall a conversation he had with me where he said he didn’t want people to cry over his coffin at his funeral, because they wouldn’t be able to cremate the wood. He then said he would not need pallbearers because there would be so many tears they would be able to float his coffin out.

Christopher had told me that his last wish was for him to skydive. A friend organised the dive. He was in the paper the day before the dive. He looked so scared and was as stiff as a board. In the video he is walking with his walking sticks and he looks so long and skinny.

I recall him lapsing into deep sleeps towards the end. I took photos of him just before he died, which I’m glad I did now. Before he died he said he wished I believed in euthanasia, but he knew I didn’t because we had watched a documentary a few weeks earlier and he had said it’s just a cop out and I had agreed with him.

I had been finding it difficult to cope. I couldn’t cope with watching him go through what he was going through, and not being with my other kids; everything was just too hard. It was just too much and I just wanted him to die. I knew that sometimes you have to give them permission to go so I said to him, “Christopher it’s all right to go.” He said to me, “The doorway is too narrow.” I remember saying, “A tunnel doesn’t have a doorway”, and he said, “OK I’ll shut up.”

I remember the day Christopher died that it was pretty clear he was going. I sat down with a book. If you came in to his room, you would find me in a chair reading a book. This was because Christopher didn’t like being touched so I couldn’t stroke his head or hold his hand. I would have liked to get into bed with him and cradle him in my arms but that was not possible.
The tension between Christopher’s father and myself had gone the day he died. I had accepted his father’s offer to pay for the funeral and the anger between us seemed to have disappeared. I believe this is why Christopher chose that day to die. He could die with his father in the room, which I think is right. He was there when he was born and it is right that he be there when he died.

I remember the funny breathing starting and the nurses commenting that it wouldn’t be long now as the Cheyne-Stokes breathing had started. I thought that’s what Cheyne-Stokes sound like. I just sat there reading a book and his father just stared at him. I knew he had died when I heard silence.

I jumped up and pressed the buzzer three times for the nurses, I pressed it another three times, but not a nurse came. Eventually a nurse came and asked if I was all right. The nurse asked me if I happened to notice the time he died. I couldn’t tell her and just pointed to her watch. I thought I was prepared for this but realised I was not. My knees were shaking so hard. Many people came to see him in hospital after he died. His sister was distraught and could only see him slowly in stages and was afraid to touch him because she thought he might fall apart.

I washed him with a friend. He wouldn’t let me wash him when he was alive and sometimes he didn’t do a very good job. I believe it was the cleanest he had been in a long while. When my friend went to change the water the hand shower came out of her hand and the water flicked all over me. My friend believed that Chris had done that to me.

I remember going with my kids to the funeral home to dress him in his camouflage pants and a black T-shirt. When they saw him the kids were a bit upset, because he was in undies with a nappy underneath. I asked for his central line to be removed because I didn’t want that in his body. I remember removing the chain with his first Eucharist medal which he wore everyday. His sister would not touch him and sat away from us. The boys helped me dress him. We dressed him in his Canberra socks, which were full of holes because that is what he wanted. He didn’t want shoes because they would cause toxic fumes to build up when he was cremated.
Kerry’s story: Mother of Alinta

Departure

I first noticed that something was not quite right when Alinta was sleepy; I didn’t panic. I was thinking she was just tired and needed a bit more sleep. Our family went to the Olympics at Homebush and Alinta was vomiting a bit. While we were there I took her to a doctor at Homebush. The doctor monitored Alinta and said she was dehydrated. We didn’t even think it was a brain tumour. Because it (a brain tumour) is so outside our realm, we weren’t going to think that is what is happening.

We flew back to Brisbane and she was vomiting on the plane. I didn’t realise I was driving around a semi-comatose child. I really did want to get back to the doctors at home. When I got home with Alinta I remember going to the local doctor and being referred to a paediatrician. I thought, ‘they could have told me that it could’ve been something to do with her brain’. You are just kept waiting and waiting and you don’t know how urgent it is. I remember Alinta had the scans and I knew that something was happening. I could hear Alinta crying and they came and got me for a meeting; there were two doctors and they said, “It’s a brain tumour.” I didn’t know that a tumour was cancer. I remember sitting there and feeling pretty disgusted because it’s in her brain and that’s pretty sickening. I didn’t know whether to ask if it was cancer.

I remember them saying that I will have to phone someone because Alinta will have to go to Brisbane for more scans and stuff. I didn’t know what to do because I didn’t have anybody. We had to get a plan together so we rang the doctors in Brisbane and my other children on the camp. I didn’t know what to say or do, I just wanted to go back and see Alinta. I went back to see Alinta and she was getting worse by the minute, her brain was swelling and she was losing breathing and they were worried about her. We had to wait for an intensive care helicopter from Brisbane to come down and pick her up and take her to Brisbane. I drove up there and was thinking she would die before I got there. I had had no sleep and was exhausted. They gave Alinta steroids. Nobody told me anything. She was in the children’s ward. It was pretty bad: she’s got a tumour and we’re waiting on a scan, I had two children somewhere else, my car was still packed with clothes from the holiday, I’ve had no food, no money, no pyjamas for Alinta. I remember I had to ring my other two kids, who weren’t there, and not panic them and try to get them up to see Alinta, but they couldn’t stay there. I was just waiting there, dealing with the symptoms, because there is no one else to do it.
I remembered Alinta having the scan and being told it was the highest grade of tumour and they would have to remove it. I believe now they have a set plan of what to do the minute that you’re at the GP’s. They only divulge a very small amount of information at a time. They knew it was a glioblastoma from the first scan and that it was malignant, but they didn’t tell me that and in hindsight that was annoying. You’re panicking anyway and you’re not kind of told anything. I would have preferred more information. I guessed that they tell you what they think you need to know and you don’t have a choice.

Exploration
The anaesthetist told me Alinta was to have a bulk reduction. I thought that is like scooping out your brain. They just use these words and you are supposed to understand and remember what they said and make a rational decision for your family. They don’t write it down, they don’t give you more information, and we’re in a hospital and don’t have access to anything like the internet. I decide everything for my family based on lots of information and I was placed in a position where I had to make a decision on little information. I was responsible for what to tell Alinta and I wanted access to all the information. I was fed little bits and they tell you some things in big words.

No one spoke to Alinta but she was always listening and I would translate for her. It was sickening for me, let alone Alinta, she just hated it. I questioned why they couldn’t change the way they spoke, instead of coming in, in an efficient manner. Not one single person spoke to Alinta nicely or with information that Alinta could understand. They might have only talked to her for two minutes because they were busy on their rounds. I realised I had two minutes to digest what they were saying. I can’t even remember all the stuff; it was too confusing. I wanted someone to have a bit more time than two minutes by her bed and at a time that was more suitable.

When Alinta came out of surgery it was like horror movie stuff. Alinta was in pain and there was a lot of swelling. I knew she had this scar from ear to ear, staples, head bandages. She had these two machine boxes: one’s a spirit level because her head is not allowed to come up further than this, because the fluid is draining from her brain. She is not allowed to have painkillers, she is not allowed to sit up, she is not allowed to go to the toilet. All Alinta thinks is, ‘she’s wet herself’. I wasn’t allowed to have a bedpan by the bed, that I could quickly slip under her, because that’s was a rule. When Alinta does wet herself it is horrible and it is a big
procedure. She’s uncomfortable and they need heaps of staff to lift and roll her, so she stays level and it’s not just her pants that are wet, it’s also her top.

I recall they were pulling a drain out and it broke in her head so Alinta had to have more surgery. I was terrified again. On the day of surgery not one person looks at her chart and knows it’s Alinta’s birthday the next day. I believe kindness in hospital is garbage. I wonder why someone didn’t say, “Oh darling, it’s your birthday, happy birthday and you’re going into surgery.” It is not the real world. Alinta’s going to be twelve and she is going into surgery. Alinta’s in hospital, I have two other children that Alinta wants to see for her birthday, should I go out and buy her a present? We’re hundreds of kilometres from home. I believe I may as well have been on Mars or somewhere to try and access the things I was supposed to provide as a mother. I was supposed to work and provide money, feed myself and my children, clothe her and me, do my washing, get my other two children organised. Not once did anyone have a plan to help me with all those responsibilities. I tried not to panic and just be the person for Alinta. You’ve got 24 hours of being her mother and just sitting by her bed like a lot of other mothers. I recall how hard it was to leave Alinta to go to the toilet.

Every step of the procedures was pretty horrendous, but it was what you had to do. What Alinta had to do was disgusting. She had to get plaster all over her head to line up for radiation. I still didn’t quite know what everything that was happening was about. I remember not being told what radiation is. I found out from the internet that Alinta could get sick three months later. So, you make decisions because you want her to be OK but you really don’t know what you are doing. I believe it was my right to know the information about radiation, maybe in a pamphlet or a book or something. I got no information unless I accessed it.

When we were going back for radiation we didn’t have a place to stay, because we were outpatients. Alinta finished radiation therapy and was home for a week then she deteriorated and was back in the local hospital. The scan showed the cancer had spread. We waited one day for her to go back to Brisbane, so that Alinta could get her academic award as she was getting Dux of the school.

Destination
We went up to Brisbane in an ambulance because Alinta was sick; she looked so sick, she could hardly walk. She’s vomiting, she’s not eating, she’s baldy, and she’s just terrible. I was told Alinta was going to die. They said maybe in three months, maybe less. I wondered how I was
going to get home because we came up in an ambulance. I had to drive home with my sister who had a clapped out car and it took five hours for a two hour trip and it was traumatic. I was thinking any minute she is going to die in the car. I didn't know how someone died. I asked the doctor, “Will I know when she’s going to die? What should I do? Do you give her a warm blanket, give her a drink, give her an icepack?”; I honestly didn’t know.

I had to come home and tell Justine and Henry (brother and sister) that their sister was going to die, do the Christmas shopping and organise my mother to be picked up. That is what juggling is. We were home for a week and I remember thinking, ‘I don’t know what to do’. We went to a holiday apartment at the beach. I tried to talk to my Mum, and Dad but you don’t talk properly because you protect them. They weren’t able to do much and although they wanted to help, they weren’t helping. Not many people come near you to actually physically help.

The responsibilities for Justine and Henry were big - looking after Alinta, there was one of them beside her every minute. Dealing with the brain thing was phenomenal, she was restless at night, she might have fits, there was agitation and fidgets, she was uncomfortable, she was biting things and couldn’t talk. I had to do the shopping at 8.30 pm to fit around Alinta. With Alinta dying I had to be the perfect parent. It’s hard enough being a parent. I felt that I couldn’t complain. I hoped that the kids would help me with it and they did, they were there doing things. We tried to do life pretty normally.

It was a lot of money and it was more than I could afford. I felt like I would have failed if I’d asked for help. I was on $200 a week because I had no pay when I was on leave without pay. How do you tell people you are a broke, single mum who can’t afford what other people can? It looks like an inequality and so they make decisions and do things as though you are successful. I wouldn’t even ask for bulk-billing because I wanted to be equal to everyone around me.

I wasn’t going to be a single mum statistic. With the cancer you are a bit more public and you are trying to do everything like everyone else. I joined the Moorland soccer club at amazing expense. You can’t say Alinta, you are going to die so we won’t join you this year. A couple of families kept doing things for us and didn’t say anything, which was really nice. One family dropped meat around every fortnight. They asked if they could organise a benefit for me and I
said no thanks. I didn’t want everyone to know I was broke. In hindsight, you shouldn’t be asked, people should just give if they think there is a need.

Work was really good, they kept in contact for the whole twelve months, with caring and kindness for Alinta and the children, which was lovely. There were a lot of people who wanted to be kind and do things, but in the end you are basically on your own, because they have to go back to their families, their houses, their gardens, their lives, their work. You get through it either through medical services or the support of paid community people.

I recall wanting to talk to a doctor and they are a protected creature. I didn’t want to make an appointment because Alinta was going to die and it could happen at any time and I didn’t want to leave her. I must have met with the doctors and they told me about palliative care. I said palliative care is where you go when you are dying and it made me want to vomit. I thought the doctor thought I was a bit neurotic, but it’s not caring, you’re going somewhere where you don’t want to go. It was like going to a cemetery and looking at a grave every day. Once again there was another care plan that I didn’t know much about. It was like an evacuation plan, go out that exit, follow that yellow card or those foot steps. I didn’t know the meaning behind it. I wondered why they don’t give you a book so you can read all about it. I believe my brain didn’t make all the connections because I have no medical knowledge. I wondered when we were meant to be going to palliative care. I remember ringing the doctor and asking, “Is she really going to die?” I was told that the tumour could drop down on her spine and Alinta could be paralysed. I panicked and was living every minute with the fear that she could drop dead at my feet.

We had kind doctors and they had to sign something and the doctor ticked the box terminal and that was pretty ghastly at the time. No one really broached Alinta about it (dying). I believe little things would have been helpful instead of asking her directly. Alinta’s eyes would turn away, she’d walk away it was too confronting. I thought doing it softer and giving her the opportunity, a person might had been able to say to her, “It’s really sad darling, are you scared?” I believe she needed kindness, empathy and getting away from being professional.

I thought that Alinta was going to go to school. I applied to be a Teacher’s Aide and had to negotiate my way through the Department to have Alinta enrolled at school. You’re making these phone calls and saying she is terminal and it’s really, really hard because you don’t want to say that. I think it was really daunting at the time. I questioned whether to buy her a
uniform; is it a waste of money, because she may only need it a week and I was broke. I thought it would have been wonderful if someone gave her a brand new uniform.

We went to school every day and I don’t think anyone spoke to her. I was with the kids, I’d sit in class, find a chair and there wasn’t room for you in the class. I felt like a big extra, watching and waiting and seeing what’s going to happen. I thought I couldn’t even use the toilet. I had to find Justine or Henry to go to the toilet. I didn’t know if I could use the staff toilet because no one said, “Please use the staff toilet.” I felt I was not an adult, but a child. I didn’t know that we could have disabled parking, I didn’t think she was disabled, just dying. I didn’t know she fitted into this category so I couldn’t go anywhere. When we got the wheelchair it was a big learning curve. It was frightening, Alinta didn’t want one and I didn’t want one. We had little information on how to use the wheelchair, how to find car parks and get out.

Having to fill in a form put me into overload. There were all the things that you needed to apply for. Once I began being paid as a Teacher’s Aide it affected my Carer’s Pension and I had to change that every week. I remember going to Centrelink with Alinta and having to fill in forms, being asked what is wrong with your child, why can’t you work, and what are your assets. I thought do I say in front of Alinta, “I’ve got no money, I’m scared.” I couldn’t say any of that, therefore, I didn’t get any help. I had wanted to do something for Alinta before she died, go to Ayers Rock or do something. I couldn’t do that because of all the form filling and trying to get the tickets. Just something for her would have been nice.

I was panicked about being there for Alinta and meeting all of her needs. I had no premonition about how it would be when she died. It was disgusting the time when she was alive trying to make a life, run the family, get the others to school, do everything, be Alinta’s friend. I couldn’t keep up with it, it was just hard and then she died. If she was in hospital someone would be looking after her. I knew my health was failing and I wasn’t getting any sleep. You don’t complain, Alinta is the one that is going to die and she didn’t complain about anything, so you just keep doing everything.

I remember going to the Carer’s Centre and finding I wasn’t eligible. I did have a volunteer from Palliative Care come to my home so I could get some sleep. This meant I had to sleep on cue but I needed the sleep so badly I would just shut my eyes and get some. I felt scared because I didn’t want to leave Alinta because she might die with someone else and who’s going to be responsible if she died with someone else and I wasn’t there? I believed there was
no choice; someone had given her a 24 hour watch with no help. I had been told home was
the best place, but where was the help? A nurse would come if you rang, but why ring? I
didn’t know what to ask for. I could bath Alinta and do all those things. You have no idea how
you are supposed to do it but you wouldn’t leave her with anyone else, she might die and
Alinta didn’t want to be with anyone else. I believe it would have helped to have someone
oversee our whole care.

My life was hard and I became more and more isolated because Palliative Care would come
into the home. You are doing the nursing and it’s isolating and devastating. The home was
more or less like a prison. Palliative Care would come out for anything, but they’re just passing
by, they are not nursing you like on a ward. There is not a word in there to tell how I had to
care for Alinta and how it felt and then she died.
Pam’s story:  Mother of Tamina

Departure
Tamina was very good at sport, excelled at dancing and loved horse riding. I took Tamina to the doctor when I noticed that her calf area was quite swollen. The doctor mucked us around for a few weeks saying it was an infection from a mosquito bite. My intuition kept telling me that this was more than an infection. Eventually, a locum took one look at her leg and sent her out for a CT scan. This was on a Friday afternoon and we couldn’t see an orthopaedic surgeon until the Tuesday. I knew that there was something seriously wrong with Tamina’s leg.

On the Monday Tamina was to perform for a tap dancing medal but I was so worried about the leg I didn’t allow Tamina to do this. A few weeks later a trophy arrived for Tamina, she was awarded Top Tap Dancer for the dancing school; it certainly put a smile on her face. When we went to see the orthopaedic surgeon, he came straight out and said you are a very sick girl, you’ve got a tumour. He asked if she had knocked the leg and I remembered that during a combined school cross country run a few weeks earlier, Tamina had fallen and knocked her leg. She got up and came second out of all those runners. I started to tell the doctor of this incident, he waved his arm and said something off-hand and walked out of the consulting room.

Tamina asked me what a tumour was and when I replied, cancer- she said she thought only old people got cancer. When the doctor returned to discuss travelling to Brisbane, he mentioned amputation. I was stunned but coherent enough to ask if it was possible to go to Adelaide as my family are all down there. Luckily, we were referred to the Adelaide Children’s Hospital. Tamina was just three weeks off her 13th birthday.

Exploration
Being isolated in Cairns and not knowing enough about bone cancer was one of the hardest things. All of the staff at the Adelaide Children’s Hospital were wonderful. Tests showed that Tamina had a very aggressive bone tumour called a Ewing’s Sarcoma on her tibia. Intense chemo started and by the time her 13th birthday arrived, just before Christmas, all her long blonde hair had fallen out -she took this all in her stride. Tamina was very sick and in a wheelchair for her birthday and Christmas.
An orthopaedic doctor returned to Adelaide from America in the New Year, where he had learnt a new technique called an Allograft - he decided that he would operate on Tamina. When she went into surgery the Orthopaedic team weren’t sure whether they could save her leg, but after a mammoth operation they were successful in replacing her tibia with donor bone. This was the first time this type of surgery had been attempted in Australia. She was in the right place at the right time. While the operation was a success, Tamina worried about having someone else's bone in her leg. She wore a caliper for a long time afterwards and had ongoing problems with the leg. Tamina said she wished that they had taken her leg off.

Originally, we were told that we would be in Adelaide for six weeks but I soon realized that this wouldn’t be the case. We ended up staying down there for almost nine months. After surgery and a long recovery there was radiation, more chemo, and then more surgery after Tamina fell over and fractured her bad leg. Tamina hated needles; she was so brave about everything else. On one occasion the doctors arranged for an anaesthetist to be outside the room in case he was needed to knock her out. I stood outside the room crying and decided that something needed to be done, so Tamina went into surgery to have an Infusaport fitted to her chest area. This was so much better, even blood could be taken through it. I could apply cream to deaden the area before any procedure was done.

At first, Tamina's friends were writing and ringing but that dwindled off. I believe that CanTeen (teenage cancer patients’ society) was a great help - the members would come into the hospital to visit Tamina and stick her in a wheelchair and whizz down the corridors with her. They would paint her bald head with different colours and put a smile on her face. She even enjoyed a few days at one of their camps in the Adelaide Hills before I brought her back to hospital for a MRI test and more treatment. I believe that all of the young CanTeen members we met were an inspiration, very strong.

Tamina was amazing - apart from the needles she took everything in her stride. The staff on the Orthopaedic and Oncology wards got to know her very well and they said she was brave and inspirational. Tamina had 18 months of treatment.

Tamina went through her teen years with this big scar down her leg. When people asked what happened she would tell them that she was attacked by a crocodile. If she told them that she had cancer they didn’t believe her.
After we returned to Cairns we had to fly to Brisbane once a month for Tamina to be hooked up to a cocktail of drugs for three days. Towards the end of treatment one of these drugs was discontinued, as it was causing problems with her heart. In Brisbane, Tamina was always the oldest on the ward, some patients were only babies. Friends we had made through CanTeen would sometimes come in and visit her and brighten her up. I worried about leaving Alicia (Tamina’s sister) in Cairns, as she was only nine at the time and was feeling left out.

We had two more visits to Adelaide for surgery. Tamina was tripped over at school, which resulted in a fracture. Bone taken from her hip was grafted onto the donor bone. After a lengthy time with a caliper on her leg and learning to walk without it, she needed surgery to correct her foot. The Orthopaedic surgeon (the same one who diagnosed her in Cairns) wanted to fuse her foot, which I learnt from the Physiotherapists was an extreme measure. The wonderful Orthopaedic team in Adelaide tried a different procedure, which meant Tamina could bend her foot with no problems walking.

**Anticipation**

After Tamina’s treatment was finished she regularly saw visiting Oncologists that came up from Brisbane. She had leg and chest X-rays done twice a year. When Tamina was pregnant with Jazmine the doctors told her that she no longer needed chest X-rays. I believe that if a chest X-ray was done at this visit, they would have picked up the relapse. We had been told that it was highly unlikely that Tamina would have a family due to one of the drugs she had in high doses. We were also told that a pregnancy could cause her to come out of remission. Half-way through her pregnancy, Tamina found a lump on a rib. She went for a chest X-ray and into surgery. The doctor told me he was almost certain that the lump was a calcium deposit on the rib. I believe that they were just looking at the ribs and not the whole picture on the X-ray, as 18 months later when that same X-ray was brought out, the lump in her chest area was visible.

I recall asking her to get a chest X-ray on a visit to her Oncologist when Jazmine (Tamina’s daughter) was a year old. I asked her when she got home how it went. She said they just asked her about her baby and didn’t examine her or request any X-rays. I remembered the Oncologist in Adelaide telling us that Tamina would need to have chest X-rays for the rest of her life and I was annoyed that the Brisbane Oncologist didn’t think that she needed them anymore.
Around this time Tamina was involved in a car accident that caused injuries to her left leg in the area of the bone graft. After many years a callus had formed in the area between her own bone and the grafted one, but now this was damaged and needed further surgery. She had numerous trips to doctors regarding this and a cough she had developed. Her doctor told her it was due to Asthma and a lung infection. He had been seeing Tamina for years, had a very thick file on her and knew all of her cancer history, yet he didn’t order a chest X-ray.

Tamina didn’t want me to come along on these visits. I would tell her to request a chest X-ray. Finally, she saw a different doctor who said he didn’t like the sound of her cough and immediately sent her for a chest X-ray. I went with her to have this done and it was then that they finally discovered that she had numerous tumours in her chest area (we weren’t told about those in her lung for many months). It makes me angry that doctors are playing with people's lives. I walked out of the doctor’s room in a daze and Jazmine crawling all over his desk. I think Tamina knew what the doctor was going to say. Tamina had been tired for many months and I thought she would have noticed the large lump in her chest area when she was breast-feeding. Deep down I think Tamina must have known her cancer had returned and kept quiet about it.

After we eventually learnt of the relapse we went to Townsville for treatment, where Tamina was many years younger than any of the other patients on the Oncology ward. When Tamina's immune system was very low she was put into a side room on her own, which was a blessing, as on the ward a few of the patients passed away while she was in there. I remember Tamina and me seeing a deceased person being taken out and Tamina handled it so well.

In Townsville, we were told different things by different doctors. One would say that there was just one large tumour and then the next would tell us that there were numerous lumps. When Tamina went into surgery, to have a minor biopsy done to determine if a tumour was a Ewing’s, she ended up in cardiac intensive care where she was kept until the next day. I asked the doctors to make sure that I was there when they told Tamina the results and they knew that I was on my way up to intensive care. I arrived on the ward just after the doctors, who were still there, had told her the news. Tamina had just come around and was confused and a bit teary. I believe that Tamina would have liked her mother to have been with her when she was told. I wondered if they did this because Tamina was 21 and had a child.
It was a difficult time as they put through what should have been a month's treatment into one week. The doctors there knew little about Ewing’s Sarcoma. They were using brand new drugs and permission had to be obtained from Department of Health (or whatever), in Canberra, to use one of these drugs. Tamina told the staff that she didn’t want any more treatment, as she didn’t think it was working and if they didn’t take out the drip she would. Eventually myself, doctors and others convinced her to continue with the treatment.

Tamina was very ill and hallucinating. After a few rounds of treatment we returned to Townsville, expecting to discuss plans for the radiotherapy to start. The Oncologist shuffled papers and walked in and out of the room and then he eventually told us that the large mass hadn’t decreased and that she had tumours in her lung. I felt like someone had hit me over the head, but I was coherent enough to ask if Tamina’s lung could be removed. The doctor said this wasn’t possible and there were no other options available. I thought he was very uncaring and I remember that Jazmine was climbing over the doctor’s desk as bad news was being told to them again!

I walked out of the room with my head spinning. I was taken aside, and then suddenly there was a social worker there for me for the first time. Prior to that the lovely people at the Queensland Cancer Fund had been a wonderful help, but no one had suggested a social worker.

Tamina was very strong and said she was going to beat the disease and watch her little girl grow up. She spoke to many Naturopaths etc. and decided to go on shark cartilage. She took it for a while and I believe it was helping.

Destination

While staying with family friends near the Gold Coast, Tamina was in agony with stomach pains and a scan showed a mass in her stomach area. Surgery indicated a rare cyst, which was removed, but back in Cairns she was still in lots of pain. Jazmine’s father broke off the relationship as he couldn’t handle Tamina’s sickness and I think this is when she lost the will to fight. She saw a female visiting Oncologist who told Tamina that the shark cartilage wasn’t working and that she was going to die. I stayed in the waiting room as Tamina said I would most probably get upset if I went in and she didn’t want me there. At least Jazmine wasn’t climbing on a doctor’s desk this time when bad news was being delivered! I knew if I’d been in there I would have been a mess, but I think it is awful that the doctor just told Tamina so coldly
when the doctor knew that her mother was outside. Around this time Tamina went downhill very fast and passed away only weeks later.

I believe that Tamina knew she was not going to make it from things she said to others, but not to me. Each time the family learnt about friends from CanTeen losing their battle with Cancer it was so hard, but Tamina took it so well. A friend from CanTeen in Adelaide was visiting the week before she passed and she told him that she wasn’t going to fight anymore - he told her that she had a little girl to fight for. Tamina kept a lot inside her. She never talked of dying to me but she did with others. She told people that she wanted her mother and sister Alicia to care for Jazmine after she was gone and knew she would be safe and well looked after with them.

The week before she died she was on oxygen and morphine constantly. An ambulance was called three times. On one of these occasions the doctors in Emergency wanted to admit Tamina and drain fluid from around her lung, but she said she wanted to go home and no one argued for her to stay. I had to fight to have the oxygen at home.

The Palliative Care team came to see us the day before Tamina died. A team member said they were coming back in a few days to talk to Tamina about her will and to do a movie for Jazmine. My friend came over the next day and gave Tamina a massage with lovely oils - as she was leaving she told me that she would be back first thing in the morning to witness the will. We moved Tamina out to the couch. When I came back inside from seeing my friend off, Tamina took my hand, "Thankyou Mum," she said and then went to sleep. A few hours later her breathing changed. I thought afterwards I would have liked someone to have been there with me at that time. Alicia was in her room as she wasn’t handling it very well. She told me, "not to be silly," when I went and told her that I thought we were losing Tamina.

I rang the Palliative Care nurse who suggested ringing for an ambulance until she got there. Jazmine - who was two years old - woke up, came out and tried to wake her Mum. When I turned on the light, I saw that she was blue around the mouth and I knew she had gone. I shook her and I think she started breathing again. I went into hospital in the ambulance and Alicia followed. She still believed her sister was alive until she arrived at the hospital and I told her that Tamina was gone. I was worried that, because Tamina had passed at home, they would want to do an autopsy, but the doctor said he could tell by looking at her that she was very sick. Tamina was so thin you could put your fingers around her ankle.

xxx
Val's story: Mother of Anthony Charles and Susie

Anthony Charles

Departure
I was separated from my husband at the time and living in Perth. Anthony was living with his father in Geelong. I first became aware that Anthony was sick when I got a call from Anthony’s father saying Anthony was in hospital and I had to ring the doctor. I rang the doctor who said he had lymphatic leukaemia.

Exploration
I remember getting the red-eye flight out of Perth that night at 12 am. I stayed in Geelong for ten days while he was in hospital. I then went back to Perth for a week and came back to Victoria with the kids and stayed a month. At the time, Anthony was having treatment at the hospital in the morning and treatment at the caravan park, where he lived, in the evening. When I returned to Perth, I got a phone call from his father saying Anthony wasn’t being treated very well at home. His father sent him over to me in Perth, on the bus.

I was advised by the paediatrician who was involved with treating Susie for Fanconi’s anaemia, to take Anthony to the Children’s Hospital in Perth. I was told he couldn’t be treated there and he’d have to go to Royal Perth. I remember Anthony was in and out of the Royal Perth Hospital about four or five times from January through to May. Anthony found being in hospital with only old people, and no friends to visit, very hard. He hated being in a four-bed ward with adults. It’s hard enough being an adult going through adult things. At 17 Anthony was not really an adult but he was treated like an adult and nothing was really explained to him in any great detail. He didn’t feel he had the right to question what was being told to him.

Adults have a different perspective on life because they can look back at life and they have at least experienced many things. Anthony was just beginning to experience life and that’s a pretty hard time to have everything pulled out from underneath you. The emotional reaction is far more gut wrenching. I know Anthony went through, “why me? This shouldn’t be happening to me,” thoughts. Anthony’s friends didn’t stay in touch because he was in Perth for five months. When Anthony came back to Geelong, the week before he died, he was probably forgotten about by that stage.
It was very hard sitting in the Perth hospital all by myself, as I had no friends or family there. I would sit there for a couple of hours and come up with some amazing excuses as to why I had to go out for a couple of hours. I would get out of the hospital, have a smoke, go to drive home and think ‘no, I can’t do that’ and I’d go back. That happened every day he was in hospital.

I was able to give Anthony some of his chemotherapy at home, which made it easier. It made it easier on his outlook on having chemo. The situation was hard because I didn’t know my way around Perth. It was a whole new ball game for me but I’m pretty determined when I decide to do something.

Seeing Anthony go through chemotherapy, the ulcer in his mouth, the dry reaching and being sick and tired all the time, was hard. I didn’t know what I could do to make things better or make him feel better about what was happening. I pushed for Anthony to be looked at and diagnosed for Fanconi’s anaemia as I had observed so many similarities between him and his sister (Susie) in their makeup, their build and their mentality. Susie had been diagnosed when she was 8 or 9. Anthony was eventually diagnosed with Fanconi’s anaemia, but his treatment wasn’t modified for Fanconi’s anaemia because when he started treatment he wasn’t diagnosed.

**Destination**

Anthony went into a coma when he was in Perth, which he miraculously came out of. After this they got him well enough so he could fly back to Melbourne, because he wanted to die in Geelong (Victoria). He came back to Geelong a week before he died. I packed up from Perth and came back to Geelong four days before he died. We came to Melbourne by train because I couldn’t afford any more trips by plane. The girls, aged 8 and 10, had trouble with him being in hospital, especially when he was in the coma. I sent the girls to their father’s sister’s place, 70 odd miles from Geelong, so they wouldn’t have to go through the death as well.

I spent most of my time at the hospital. In the last four days Anthony knew he was dying. The specialist sat down with me and asked if I wanted more treatment which would keep him alive for another three or four months. I remember saying, “What the hell for? He’s been through enough already.” The specialist explained to Anthony that he didn’t have long to live, that he could have more treatment but “Mum thought it wasn’t worth putting you through it.” Anthony decided that Mum knew best. I believe if I’d made the decision to keep him alive, it
would have been for me and not him. I remember him dying in my arms, which was really
good.

At the time there was so much going on. It was hard coming back from Perth not knowing
where I was going to live and where to send the furniture and wanting to spend the last four
days at the hospital. After Anthony died, I then had to sort out the funeral. I then had to sort
myself out and where we were going to live. Despite this, I feel I coped. I believe a mechanism
kicks into gear and says ‘you just have to get on with it’. I found a place to live and got the kids
settled into school and into a routine again. Life goes on.

Susie

Departure

For Susie it is a long, long story and her treatment really started just before she started school.
She was diagnosed as being growth hormone deficient when she was five. Susie was given
injections of human growth hormone for two years, which was then banned worldwide
because of the threat of Creutzfeldt-Jakob Disease (CJD). We then reapplied for the synthetic
growth hormone, about three years after she had come off the human growth hormone, and
she was on the synthetic hormone for probably 18 months. I remember I had to deal with the
possibility that Susie might get CJD.

From the time Susie was 13, I used to sit and talk to Susie about Anthony’s death and how it
affected her. I would mention to her that there was a possibility, somewhere down the track,
that she would develop leukaemia as well. I knew there was no cure because of the Fanconi’s
anaemia but I never told her that at that point in time. I wanted her to be prepared. I believe
the more information you have about something the better prepared you are.

We had been told that Susie would develop leukaemia about the same age as Anthony. She
didn’t develop it until she was 23, so as each birthday rolled around we had to have a bigger
birthday party in case we weren’t there for the next one. When Susie was eventually
diagnosed she said, “Thank Christ now I’ve got nothing to worry about.” I was surprised at the
relief Susie showed when she was finally diagnosed. I think because of all the preparation we
had been through, Susie was accepting of the diagnosis. I had not been prepared for
Anthony’s journey but Susie and I were prepared for Susie’s journey. I believe I had been naive
with Anthony about what chemotherapy can do to the body.
Exploration

Susie was treated in the Children’s Hospital. Susie had two lots of chemotherapy in 9½ weeks, which nearly killed her. I was able to relate to her and give her suggestions to take her mind off it. I sat with her from 8 o’clock in the morning to 8 o’clock at night. With Susie I knew exactly what was going on and had no reservations about sitting in her room for 12 hours. The doctors always consulted me and I had input into the decisions about what happened to Susie. It made it a lot easier the second time around being more involved with Susie’s treatment and doing things for her. I was also more aware that I could ring the doctor and say this is happening and what should I do. With Anthony I probably wasn’t aware that I could do those things. I developed a good relationship with the staff at the Children’s Hospital, because I had to be a ‘hands on’ person. Being a ‘hands on’ person means you learn more and can actually do some good. I think openness between the child and the parent is the most important aspect, no matter what the age.

The Children’s oncology ward was pretty old. At one point when Susie was really, really sick she was in a ward with eight other kids aged from 18 months to 10. Susie didn’t really want to be in the presence of little kids crying and moaning and carrying on and it was all very upsetting for her. It was hard being a teenager like Anthony and having to go through cancer in an adult world and it was as equally hard for Susie to go through cancer as an adult in a kid’s world.

The rest of the family coped in different ways. Susie’s stepfather, whose wife had died of cancer, did it pretty hard as it opened up a lot of raw wounds. Susie’s sister is like her and had pretty good coping mechanisms, her brother only saw Susie twice in hospital because he couldn’t do it, and her father was of the opinion she wouldn’t die so he was of little help.

When Susie came out of hospital I was able to talk openly about dying with her. Being able to talk openly about dying is all part of the preparation and grieving you go through when someone dies. Susie organised her funeral before she died, picking out the coffin, writing a eulogy, working out where to have the funeral, whether to have a funeral celebrant or a minister, meeting the funeral director. This helped immensely because after she died it was just a matter of processing these things together. I believe it gave Susie peace to know that when she died things weren’t going to be left in the air. Things were going to be done the way she wanted them done. Susie was concerned that people who had gone before her,
particularly her brother Anthony, would not recognise her because they hadn’t seen her in years. I suggested they do up a name badge with her name and put it on her. She ultimately went to her grave with a name badge on her.

I believe Anthony’s journey was a lot harder because we weren’t prepared, didn’t know enough and I didn’t stretch the boundaries very much. He was 17, his life was just beginning and out of the blue it was chopped from him. His quality of life in the eight months he had leukaemia, wasn’t as good as Susie’s 11 months. Those 8 months were really pretty horrific.

When we came home from hospital after the 9 ½ weeks, Susie made the decision to have her catheter taken out so she could get out and do things because she was not going back to the Children’s Hospital for treatment. She was home for three weeks when a good friend took them to a theme park in Queensland for a week, which Susie enjoyed. Susie was in a wheelchair at the time. We had a wonderful local GP who, every time we wanted to do something extra, would make sure Susie was topped up with blood so she had the energy to enjoy it. He particularly made sure she was topped up for her birthday party in November so she could enjoy it. I remember that playing bowls before she died meant a lot to her. She would have a blood transfusion the day before she played so she was pretty much fit. We did some amazing things and trips, before she died, with the support of friends and neighbours. We made the best of our family Christmas that year. Everything was kept as normal as possible.

Susie wanted to find out if there were other young people in the area with cancer. I took her to a Cancer Support Group and found out everyone was over 45. There was CanTeen, but it was Melbourne-based, and we were a 3½ hour drive from Melbourne. We had to be our own support group for Susie, with friends and neighbours. The support Susie received from friends was really good, there wasn’t a day when someone didn’t ring her up, or come and see her.

You can look back at some things and laugh. I remember when Susie was quite adamant that there was a pile of wood on the side of the bed. I tried to convince her there wasn’t - eventually I just gave up.

Destination
Because we had time to prepare for the next step, which was her dying, Susie had to make the best of that as well. Susie was in a coma before she died. She was put on a morphine drip and
all other medication was withdrawn. I stayed with her on the Saturday and Sunday nights. I remember on Monday evening I just needed to go home, as badly as I needed to be with her at the time. Susie was in a coma and Anthony had been conscious when he died; he knew I was there. He was talking to me a few minutes before he died. I knew that if she died that night I wouldn’t be with her. She died in the early hours of Tuesday morning.

Tania’s story:  Sister of Susie and Anthony Charles (Fred - Tania’s nickname for Anthony)

Exploration
I remember bits and pieces of Anthony’s journey, like the lumbar puncture, moving to Western Australia, my Mum giving him chemotherapy at home, his vomiting and all that sort of stuff. My main memory before we moved to Western Australia was the lumbar puncture. I remember him lying there and the doctors telling him he had to lie very still and seeing them actually screw the needle into his spine and stuff. The doctors were hesitant about us seeing that because he was so young.

When we moved to Western Australia I recall my Mum giving Anthony his injections at home and Susie and I having to have gowns and gloves and all that sort of stuff. He would get sick and I remember him lying on the kitchen floor in tears, because of the pain. Fred then got sicker and went in to hospital. Susie and I would go and visit him at night. At this stage he was unconscious. When he came back from the coma he fought the nurse. He wanted a drink and the nurse only gave him ice. He was like, ‘fuck the nurse’, he wanted a drink and not just to chew on ice.

Destination
I remember they got him well enough to fly to Melbourne and he died within days of being back there. I remember having nightmares after Fred died; I thought he was turning the bedroom light on and off.

Susie
Departure
I knew Fred he was sick at the time but the thought only really hit home later, when we knew Susie was going to get cancer. It was made all the more public to her and her friends in Year Seven. I remember if Susie got a knock or a pain she’d get really upset. The kids at school
couldn’t understand why. I recall my Mum organising a meeting at the school and the girls at
the school were told there was a possibility of Susie dying sooner rather than later.

We had known what was happening with Fred and we thought he had gone into a remission
type thing. Susie’s thing was she was always going to beat it because we thought he had gone
into a sort of remission. Because Susie’s illness was more recent and I was older I remember
more. Fred’s treatment wasn’t as much in my face as Susie’s was. Susie and I were in the same
class at Tech and I shared a room with her. We were pretty much together.

When Susie was first diagnosed it was just after my wedding. Susie was hearing train noises in
her head and the doctor said to take her straight down to the Children’s Hospital. My mother
and I went down and slept on the couches there that night. A nurse shot the gun and said, “So
she’s got cancer.” We said, “What? She hasn’t even been given a diagnosis yet.” We were
given the diagnosis the following afternoon.
The diagnosis wasn’t a big shock because for the previous ten years we had known it was going
to happen. It was a relief for everyone once they knew. I thought Susie knew deep down in
her mind it was going to happen; as much she was originally first upset when she was first
diagnosed. I didn’t want it to happen, but now that it was happening it was like, where do you
go from here?

**Exploration**

While it was happening some things got put on the backburner and we all chipped in to make
it as easy as possible. At that time what was happening with Susie came first. It was just a part
of our lives that we had to deal with; we didn’t have a choice. Part of the job was to make it a
bit easier for my Mum. My husband and I would go to the hospital on the weekends and help
with Susie. I would help her with her bath and that sort of stuff. She couldn’t do it herself and
Susie would rather one of us than the nurses do it. My Mum would take my two little kids and
go away for the weekend or go out. It was just something that we had to do. There was never
any, ‘oh shit, I’ve got to go back to the hospital this weekend’.

Susie hated the Children’s Hospital. She had one particular nurse that she hated. Susie would
get very quiet, because there were lots of little kids and she couldn’t do the things she wanted
to do like swearing, drinking and smoking and all that sort of stuff. She had some of her
movies there and she constantly had to pause ‘South Park’ when the nurses came in, because
it was not an appropriate movie to have in a kid’s ward. I believe Susie chose to go to Bairnsdale when she got sick again, because she hated the Children’s ward.

Susie, whose mentality wasn’t as high as a normal 24 year old, would cope by doing kiddy things like art and crafty type things. There was also someone with her all the time so she had some adult conversation. She didn’t mingle with the other kids. I felt sorry for her because she was in the isolation part of the Children’s ward and couldn’t go anywhere. I thought she’d go stir crazy. So, I used to ring her during the week, but there would be times when she was just too tired and fell asleep on the phone. I used to take the kids in to see her on the weekend and there was a stage when Susie didn’t want the kids to see her because she had sores from the nasogastric tube.

All of my friends thought Susie was fantastic. My friends knew Susie was going to die and as far as they were concerned Susie was a barrel of laughs. Friends in the medical field couldn’t believe how Susie held up with what she was going through. They couldn’t believe how positive she was, knowing what other people had gone through. Having friends in the medical field helped me, because I could quiz them. If I didn’t have friends in the medical field I would have quizzed my Mum more; my Mum earbashed the doctors and I would have earbashed her.

Fred didn’t go through as much sickness as Susie did. I never saw him get right down to ‘skeletal’ like Susie did. I was in every weekend with Susie and I saw her go right through to rock bottom, and then come back up again and then go downhill again. Fred, even when he was in a coma, he didn’t look as sick as Susie did. At one stage they had to stop her treatment because she was so skinny. It was hard to watch her when she was really sick and she had little sores and stuff. I would wipe her nose and Susie would be hating it. I would have stuck my arm out for a bone marrow transplant, even though we were told it wouldn’t work.

**Destination**

I knew it was only a matter of time before Susie died. I would hope that something would happen but obviously it was just wishful thinking. I remember one of the hardest things for me was when Susie was back home and she was reading her eulogy to me over the phone. She read it like she was reading a book to me over the phone. It made it more final, more definite. I said, “OK, put Mum on the phone”, because I didn’t want to talk to her. The stuff Susie had written into the eulogy was her terminology.
It wasn’t a horrible journey because Susie would say things to make you laugh; her normal, everyday, stupid things. I also knew that Susie was dealing with it so well, she never went into a state of, ‘why me?’; not around me anyway. She was still out making jokes before she died. Susie had met the funeral guys before she died and asked them to wear Hawaiian shirts. One of her final wishes was to sit in the coffin after it was made but she missed out on that, she died a day or two early. There were photos taken of her afterwards in the coffin. I’m sure she would be happy about that.

When Susie was in hospital and was going to die I was devastated. We drove down that night and stayed at the hospital. We stayed till about one o’clock that night and all the next day. By this stage Susie was unconscious. My Mum was more concerned that we didn’t need to be there and we didn’t want to remember her like this. I was stubborn like my Mum so we stayed. We left that night; I didn’t want to leave. I spoke to Susie and left and pretty much said goodbye. Susie died the following morning. I would have preferred to have been there when she died, although I had spoken to her the week prior, so it wasn’t like ‘oh my god it’s happening and I haven’t spoken to her’.
Denise’s story: Mother of Brenton James

Departure
I first thought that something was wrong when I noticed Brenton’s left eye was turning in. I asked him what was wrong with his eye and he got quite cranky and told me I was as bad as all the kids at school. That night I covered his right eye with a piece of paper and he told me he couldn’t see anything. I asked him how long it had been like that and he told me he couldn’t remember. The next day I took him to the optometrist who spent a long time looking in both eyes. We were told he had a growth or tumour in his eye and he would have to go to the Eye and Ear Hospital in Melbourne. We headed off to the Eye and Ear Hospital that afternoon and the specialist there said they were pretty sure it was a melanoma and they would do further tests. After a few more tests, it was decided to remove his eye in December 2004.

Exploration
We were lucky to be able to stay in Ronald McDonald House when Brenton was having his tests and at Steve Vizard House when his eye was removed. He was only in hospital for three days and four days after the operation he played a round of golf with his mates and said to me, “Mum it’s only an eye, I’ve got another one I can get on with my life.”

Anticipation
I remember the follow up appointment in January and the specialist saying as far as they could tell they had got everything and he had as much a chance as any other child or adult of getting cancer. I thought this was a big relief; we had had our big fright in life. He was coping well and we could just get on with our lives. Brenton received a prosthetic eye, and he managed it really well. Life went along as normal and he did everything his mates did.

Destination
I remember in June/July 2005 Brenton saying he couldn’t manage his work experience with his father’s work anymore because his stomach hurt too much. I took him to the local Chiropractor who thought he needed an MRI. The Chiropractor organised it with the local doctor. They discovered a substantial secondary tumour in his liver. I wished that was one of the things that hadn’t happened. I thought maybe he should have been getting regular checkups and it would have been seen earlier. That wasn’t to be. I believe it was more of a shock because we thought he had escaped when he lost his eye.
We went to the Children’s Hospital and he was referred to a top specialist at Peter MacCallum. When we went to see the specialist, without really saying it in front of Brenton, they said there was no cure. The specialist said because it is in the liver and was big it would probably spread everywhere else. The only option was an experimental treatment from America, which was like a gauze which cuts off the blood supply to the tumour. The tumour swells and then it starts to die. When it shrinks down to a smaller size, you can start to treat it. The family said we would give it a try. After the experimental treatment his liver continued to swell, his stomach became bloated, his legs were full of fluid and he was fading away. He was having the increasing look of someone who has not got long to live. I was told his kidneys were shutting down.

I believe some of the interns were just finding their feet and they didn’t know how to deal with these things. I especially wanted to shake the young doctor who was trying to say Brenton was critical and was going to die, he just rambled on and on. I wanted to say, “For Christ’s sake just say it.” We had a wonderful team of social workers who could have organised computer links with his school mates, study and lots of things but he got sick fairly quickly in the end and he couldn’t be bothered with schooling and he didn’t want his mates to see how sick he was. The social workers were great, from my perspective, they kept me in the know of everything that was available to me. I was lucky with meals because I had a niece who would sit with Brenton while I shopped or made myself something or she would bring food from the café where she worked. My work paid me the whole time I was off work and I couldn’t have coped and would have been in dire straits if they hadn’t.

Brenton’s father and sister were still in our family home and we didn’t get to see them much. I found it lonely and difficult when those around me were trying to help but were not part of the inner circle.

Brenton was flown home a couple of times by Air Ambulance so he could be around his family for a while. We were set up with his medicines and he was having morphine with a pump continually. He had a couple of days where his friends visited and he made everyone feel good saying, “I’m all right, I’ll be right.” It was obvious to those close to him that he was suffering but he never, ever let anyone see that if he could help it. I remember watching his best friend coming down the stairs backwards and holding him and Brenton was holding on to his shoulder. You could see that they loved each other and that Brenton’s friend didn’t want his
best friend to die. They kind of wanted to show each other how much they loved each other, but being teenage boys that’s a bit of a no go sort of thing. It was the most emotional thing.

Brenton was only home a couple of days when he started to get a temperature and his specialist said he wanted him back at Peter Mac. Brenton and I had wanted to go back there because he felt safe. He had developed a special relationship with a nurse there who treated him as a teenager and as an equal, not someone who fusses over him and treated him with pity sort of thing, she gave him as good as he gave her. If he grumped she’d grump back and they would be back and forth at each other and he would have a grin all over his face. She stood out and he felt safe. I remember all his friends coming out to the airport to say goodbye and Brenton could barely put one foot in front of the other. He would not let the ambulance guys help him up the 6 or 8 stairs of the plane. It took him lots of minutes to get up the stairs. He stood at the top of the stairs and waved to his mates and they all waved back. It was very sad. His friends wanted to come and see him and he didn’t want them to see him as he was. It was more for their sake than his; he didn’t want to cause them any heartache.

It was pure love that kept me going after we found out he was crook again. He never asked me, “Mum, am I going to die?”; I could never say to him that he was going to die. I think it was something we understood between the two of us. We understood that we were on a journey together that neither of us wanted to go on and we were going to support each other on the way. We had a very strong bond, which a lot of people would refer to as soul mates. I believe he and I were one, he knew what I was thinking and I knew what he was thinking. At times he would say things to me like, “My beautiful Mum, you know, you’re so good to me,” and “You’re looking after me and all that sort of thing.” I felt proud that we could talk about absolutely everything.

I remember him telling me he didn’t want to die a virgin. I believe he did ask some of the girls at school that if he was going to die would they have sex with him. I thought it was part of being a teenage boy. He knew he was going to be missing out on one of the greatest things in life.

The night before he died his stomach was swollen up and he was finding it difficult. They had inserted a huge needle and were trying drain the fluid and couldn’t find it. I was holding his hand. The doctor was saying, “I’m sorry Brenton” and he had said, “That’s all right thank you for trying.” He was the most wonderful patient.
I have had medium sessions with him and in the last one he told me that he prayed they wouldn’t take him. He told me he was scared and in pain and frightened of dying but he didn’t want anyone to know that. I remember being asked by one of the doctors that if something happened to Brenton how much effort did I want them to put in to keeping him alive. I saw how much pain he was in and said if he passed away he was to be left to pass away. That’s when the reality hit and a girlfriend brought my mother and husband down to Melbourne.

I had been with him practically 24 hours a day 7 days a week and was exhausted. At 4.30am on the morning he died, I asked my husband to sit with him because I was exhausted and needed a sleep. At 7am that morning I wanted to go back to my boy and when I walked into the room I could tell he had already passed. My husband said, “He can’t be, I was just talking to him five minutes ago.” I knew he had gone because the life had gone from his eyes. My husband just yelled, “No it can’t be.” I raced out of the room and found a nurse and said “My son’s not breathing.” They came in and said, “Yes, he’s gone.” I had wanted to hold his hand and be there when he died. I had known how critical he was, but I never suspected for one minute that he would go without me. I was not ready for it.

Brenton told me, through the medium, that he had wanted to wait for me but he couldn’t. The medium told me he said, “My Mum had the voice of a rhinoceros, and they could hear out to the Gods, she even yelled at me after I passed away. Why didn’t you wait for me?” He said he stood beside me at the bed and yelled back at me, “It wasn’t my fault I tried to wait.” They were very good with allowing us to spend as much time as we wanted with him. The specialist came in saying stuff to him, which was so lovely. He spoke to him as if he was still there and could still hear him. He said things like “Sorry mate, we tried to save you, we did our best” and all that sort of thing. I found it difficult to go home and leave him in the hospital morgue. I hated the fact that he was not coming home until the next day.
Cathie and Heather’s story:  Sister and Mother of Paul Vincent

Paul was a nice kid, the sort of kid you would look at and say he hasn’t got any faults, he wasn’t a larrikin, he wasn’t naughty, he was good fun, just an average Joe Blow, everyone liked him.

**Departure**

I (Heather, mother) first noticed there was something wrong when I noticed a lump on Paul’s neck. Initially, I thought it was glandular fever because there was glandular fever at the school at the time. The blood test showed it was not glandular fever and we were asked to bring him back for more tests. I realised afterwards that he had little spotting on his arms and legs. I wondered how long he had had leukaemia before we noticed it. At one stage I wondered whether because I had him late in life that could have caused the leukaemia. The doctor said that had nothing to do with it, that it was just one cell that went berserk, multiplied and keep multiplying. My husband took Paul down to the GP and the GP said he was pretty sure Paul had leukaemia. The GP sent him to a specialist who worked in the same building and who confirmed it was leukaemia, although he didn’t know what kind. Paul needed to go to hospital for more tests and he was diagnosed with acute lymphoblastic leukaemia. I remember when I was told it was the worst thing.

I (Cathie, sister) recall knowing that it was not glandular fever because I noticed little red dots on Paul’s arms and white fingernails, just telltale signs that made me think it’s not glandular fever, it’s leukaemia, but I had to sit back and wait for the diagnosis.

**Exploration**

I (Heather, mother) remember Paul was reverse barrier nursed and we had to scrub up. He was only allowed his immediate family and two of his friends. He lost his thick fluffy beautiful hair. He never had his hair grow back. The treatment was the horror part of it, developing terrible mouth ulcers down his throat and not being able to eat. He didn’t like the taste as everything was going through an ultraviolet light. In all the treatments he had 18 lumbar punctures and seven bone marrow tests, which were pretty awful. Some of the treatment he couldn’t take - with the platelets, he came out in a rash and they gave him Phenergan, which upset him. All the treatments seemed to fight against each other. Paul had radiation, which was another thing that made him horribly sick.
I (Heather) remember him being referred for experimental treatment and the specialist telling him they had tried everything and Paul saying “if this treatment doesn’t work that means I will snuff it.” That was his comment, and that was it. His terrible treatment burnt his eyes. During the treatment a doctor came to his room to see what his sight was like and Paul couldn’t even close his eyes. It was terrible and the doctor took some horrible photos of him. The doctor wanted to take him from his room to test his eye sight properly and the nurse told the doctor that Paul would leave the ward over her dead body, that he had been through enough and that he was not leaving the ward just for the doctor’s research.

I (Cathie) remember him screaming out “My eyes are burning” and screaming out for eye cream. He was in pain and they gave him more new treatment, which burnt his eyes more. I believed it was cruel and I asked my father why he was doing this.

When people asked why I (Heather) let him suffer, it was because you are always hoping they will get a cure. He was in a six bed ward with older men, which was pretty awful. I recall one man being next to him who was nearly dying. It was a normal oncology ward in a public hospital and it wasn’t set up for teenagers. Paul played UNO to keep his mind occupied. The staff were excellent and worked hard to make his stay in hospital comfortable, they knew it was an awkward place to be. They would try to get him a single room and if not they made sure he had a TV and a phone so his mates could ring.

I (Cathie) believe that because I worked in the hospital, and people I had trained with worked there, and the fact that he was young, meant that his care became a little more personal.

In the nine months of treatment Paul spent more than half the time in hospital. He would have spent more time in hospital if they had not been able to give him some of his treatment at home. I (Heather) think the doctors were wonderful because they knew he wanted to be at home.

I (Cathie) used to drive over at about 10-11pm at night, it was about a 20 minute drive, and give him his treatment. I had a little baby at home so I would set the alarm, get out of bed, give him his treatment, hang around to see if he vomited, give him his Stemetil, go home, get up, call in on Paul, give him more Stemetil, go to work, call in on Paul, give him some Stemetil, go back home, come back again. It was exhausting.
I (Cathie) let a doctor have it once because he insisted Paul have his lumbar puncture sitting up and Paul always had it lying down. That was the only time I ever saw Paul insist he was not having it. I believe about six months of aggression came out and I told the doctor, “Don’t you dare tell him he has to have his lumbar puncture sitting up, if he wants to have it lying down he can.” I contacted a doctor who used to work in the oncology department and he came and did the lumbar puncture for Paul lying down. From that time on this doctor would come and do the lumbar puncture lying down. I believe the doctor who insisted on Paul having his lumbar puncture sitting up was just a doctor, there was no association, no feeling, he was cold and that was his job. On the other hand, the doctor who came and did the lumbar puncture lying down, was a family doctor and even though he was in a different department he used to visit Paul and had himself rostered on the weekend he died.

When Paul came in for day treatment there was one waiting room for everyone and people were allowed to smoke. Paul couldn’t stand the smoke so we had to wait by the lifts and the phone for his treatment. Even then the cleaners used to come and stand next to him and smoke when they were on the phone. I (Heather) remember once, when he was very, very sick saying I wish it had been me and not you and he said he wouldn’t wish this on his worst enemy. Paul felt sorry for the little kids who couldn’t understand why they were going through what they were. I wonder if things have improved for teenagers now. I know there are new wards but I’m not too sure about teenagers.

There was a 19 year old boy who came through surgery when I (Cathie) was working the other day, he had leukaemia and I knew he would go back to a surgical ward with three old men who were hacking and coughing. I believe there is a gap, you’re either in the paediatric wing or you’re in between, you’re neither this or that, and you can be in a ward with people with emphysema and germs.

Paul was the sort of kid that took everything in his stride and casually. He insisted I (Heather) continue on with tuck shop and scoring for the cricket team throughout his treatment. One teacher told me he must have been put on this earth for a reason and that seeing Paul bright and breezy, no hair, and looking pretty awful pulled him to tears, particularly when he thought some of the kids he taught would end up in gaol. I remember one mother whose daughter was in hospital with cancer saying to me, I must be so proud of my son; she said her daughter was complaining all the time and that Paul didn’t seem to worry at all.
He never really went back to school but as soon as he was out of hospital he was on his bike and down to see his friends. His mates were wonderful, they would ring him up and come and see him as soon as he was out of hospital. Some keep in touch even after all this time. Although one mother would not let her son visit Paul because she thought it would upset him too much.

It was hard for Paul with physical activity. He was not allowed to play football. He played cricket with his friends when he couldn’t see properly and his friends let him even though they probably lost the game because of him. He went tenpin bowling with his father and just brushed his leg with a bowling ball, and the bump came up in a huge bruise, which was swollen and black until he died. The doctor said if it had been his head he would have had a cerebral haemorrhage and died (Heather).

After Christmas I (Heather) gave up everything because he was really bad. I recall a nightmare trip to my brother-in-law’s farm. Paul had wanted to go and he got very sick and we had to leave. It was night time and raining. He was so sick.

I (Cathie) think it was his goal to go there and he reached it even though he was so sick. The doctor I had worked with for donkey’s years called me aside to ask me how my parents would take the news (that Paul was dying). I suggested that he be honest. Dad was angry because he thought I knew more than he did, and I had a secret. It put a wedge between me and my father for a while. In addition, despite the fact that I told my father, “You can’t catch leukaemia” my Dad believed that Paul had caught leukaemia from Ray, my father-in-law, who had died the previous year from leukaemia. I feel he wanted to blame someone. He thought it was my fault because if I had not married my husband, Paul would not have caught leukaemia. This created another wedge. He also used to blame other things for Paul getting leukaemia, such as sitting to close to the TV and the microwave.

The whole experience was like déjà-vu. I (Cathie) had cared for young kids with cancer and used to go and play cards with them after work. Then my father-in-law got leukaemia and I went through all that with him and then when Paul got leukaemia it was like, here we go again. I went through a really hard time with it all; I had a young baby and it felt like I spent my whole life at the hospital working, breastfeeding, visiting Paul. When I wasn’t with Mum, Dad and Paul I was visiting my mother-in-law who was two streets from the hospital, who had lost a husband and didn’t know how to cope. I got down to six and a half stone and was really thin.
and worn out and they wanted me to get well and strong because I was a match for Paul’s bone marrow.

Paul needed to be in full remission before they could do the bone marrow transplant and he never got into full remission. I knew he would never go into full remission because it was an aggressive leukaemia. I couldn’t share that with my Mum and Dad because it wasn’t for me to tell.

One of the young doctors did tell me (Heather) the cancer was very aggressive and not to get our hopes up just before he went into reverse barrier nursing. He was the only one who would say that, the others all said with treatment these days there could be hope.

Destination
From the time he had trouble with his eyes and when he bruised himself with the bowling ball, his whole system was breaking down. I (Heather) knew he was going to die when they put him in the room behind the Sister’s desk. I (Cathie) knew he was going to die because my father-in-law had died (of leukaemia) in that room. I felt a real sense of déjá-vu, a feeling of here we go again; here I am sitting here again. Twice my husband and I (Heather) stayed in the hospital two or three nights because they didn’t think Paul would make it through. They put beds in the room with him. I (Cathie) recall that Paul would get sick and pick up a little bit and then get sick and pick up a little bit again and so it was hard for my father to see that he was really going down. My father kept a positive attitude and was not realistic about Paul dying. I felt I couldn’t say ‘Dad you have to be realistic here, he’s dying, there’s nothing you can do for him’. It made my gut wrench to think it’s not going to do him any good. He was in denial that Paul was going to die; he just couldn’t accept it. Paul and his father were best mates and Dad thought he was the grandchild he would never have because he was born later in life when Dad was 49.
Heather and Trish's story: Mother and Sister of Paul Vincent

Departure
When I (Trish) first heard that Paul had leukaemia I was positive he was going to live. I had thought the word cancer meant they were going to die but leukaemia was a different word and it really wasn’t that big a deal. Although, I (Heather) knew about leukaemia because I had seen someone at my daughter’s wedding who had leukaemia, who looked awful and who died shortly after the wedding.

Exploration
I (Trish) remember going to see him in hospital just after he was diagnosed and thinking you’re only a baby, just a little boy. I could never forget him lying on the bed in his shorty pyjamas, with his legs tucked up, chatting just as normal. When he was first diagnosed he was just a young kid running around, kicking a footy and playing cricket and suddenly the same good looking boy is in a hospital bed. It was pretty hard and sad because he sometimes ended up with old decaying stinky old men. I wondered why would you have a child in a ward with old men?

I (Trish) remember people looking at him because of the purple radiotherapy marks on his bald head. Once when we were shopping he said, “What are you looking at?” to a stranger. We all lived on hope for a long time. When he went into barrier nursing I realised that it wasn’t real good, it got stricter and stricter when we went to visit. I recall one time when I was shopping with him just before he died and him saying, “I am not going to die you know,” and I was thinking, what do you say? (Trish).

One of the positives was the relationship he had with a nurse who just loved Paul, she was so positive and was always really chirpy (Heather). He was so brave, even when he was really crook, he never let on how crook he was. I (Trish) thought he was amazing. I remember how I was there once and held his hand when he was having a lumbar puncture and he nearly broke my fingers. He never let on what was going on inside him despite the magnitude of what was happening to him. After he had died I (Trish) reflected on the fact that he never complained, despite all the stuff he went through. He was wonderful to visit, even when he was the sickest of sickest, it was as if there was nothing wrong. Even in the early times when he went through his initial chemo, which was probably a rude shock to him. Sometimes you would go in and he
wouldn’t even talk and you would sit there and hold him and hold his hand or wipe his forehead with a cloth (Trish).

We played a lot of UNO in the hospital ward and it drove them (Trish and Heather) nuts because that is all he played. There was no TV, no Walkman things back then, so what else could he do when he was lying in a hospital bed feeling crook? I have never played so much UNO in my whole life (Trish).

I (Trish) found it difficult to visit Paul when Dad was there because he went through all this religious stuff, which was pretty full on. I felt like my Dad was putting thoughts into Paul’s head that he was going to die or something. Dad used to go in every morning when Paul was still asleep and he would pray using the Rosary beads and Paul would say to me afterward, “What did Dad do that for? It is not as if I am going to die” (Heather).

I remember talking to him about kids throwing rocks onto the railway line trying to derail the trains and I said to him, “It is a pity they didn’t get leukaemia instead of you.” He told me that he was lucky and that those kids probably wouldn’t have parents who would want to be with him all the time and what a horrible journey they would have (Heather).

I (Trish) believe he went in as a child and died as a man, he had started to grow whiskers. It was not just Paul maturing physically, it was also the fact that he was mature about the way he handled all the treatments and that. Paul was on a ward with farty old men, having a priest pray over him and his father praying over him with the rosary beads and I wondered how that would affect his attitude. He never said, “Oh not another needle” or “Not another test.” Even in the treatment with his chemo Paul’s veins were breaking down and the doctors were there for ages trying to get the cannula in, they were going to have to start on his feet (Trish). I (Heather) remember the brush with the bowling ball and his legs became so swollen they had to cut his jeans off. We all thought, poor little boy.

The treatment was pretty full on physically and emotionally for us all, visiting him in hospital all the time. It was so hard putting on a face all the time when I (Trish) visited and then collapsing afterwards when you got outside.

**Destination**

It wasn’t until after Christmas that he got really sick again and he went into hospital and they (the doctors) said they didn’t see him having long to live. I remember thinking, “Oh my God he
is really going to die?” He died in the February (Trish). It was terrible when he died and I think we were relieved when he drew his last gasping breath because he wouldn’t let go (Trish).

Paul kept his positive attitude for the whole time. On the day he died he talked about getting his Dad’s old car when his Dad brought a new one. He died in hospital of a cerebral haemorrhage in the end. He had a huge haemorrhage and fitted and they gave him Valium and resuscitated him. I (Trish) abused them for doing that; he lived for another six hours leaking from every orifice. My father was cranky with me as he said he might live. That is probably the worst memory I have, the way he died. I’ll never forget the look on my Mum’s face sitting there watching him, every breath Paul took my mother took. I thought, this would not be happening if they had just let him die which would have been a lovely way to say good bye.

I (Heather) just wanted his suffering to be over. The sitting and waiting made it worse.
Departure

I (Alan) remember Naomi first noticed a lump on her groin the same year she changed over to Law at University. The doctor was not sure what it was and he thought it might be viral. The lump didn’t settle down so the doctor thought it might be bacterial. He put Naomi on antibiotics and did another blood test. During this time she had to go to hospital to have her wisdom teeth out and she had to stay overnight due to problems with bleeding from the gums. Naomi went up to see the GP again who thought something else was going on and referred her to a General Surgeon. Naomi was admitted to hospital for tests and the day she went in she developed a rash. The test results came back that she was positive for glandular fever. She was referred to a haematologist the following week.

A couple of days later she was at home with her sister Rebekah when she developed sudden breathing problems and palpitations. I (Rebekah) thought that I needed to take her to the doctor because I thought there was something going on. By the time we got to the doctor I actually had to help her into the surgery. When I got to the surgery I didn’t click that things were really bad. The GP handled the crisis really well. The GP organised an immediate chest X-ray. By the time we arrived for the chest X-ray Naomi was in so much agony that they had to get a wheelchair to take her into X-ray. I was told by the nurse to wait there for my mother. I thought that was unusual and maybe it was something serious like pneumonia or something.

My mother had been told by the GP to take Naomi straight to the haematologist’s. The specialist waited in his office after hours to see Naomi. I knew it was something really serious but I didn’t think it was cancer. My wife and I (Alan) took Naomi to the haematologist’s, who told us she either had acute lymphoblastic leukaemia or Burkett’s lymphoma. Naomi was admitted into hospital immediately and started on drugs to stem what was happening and given a bone marrow biopsy. The next day she developed a petechial rash and she was admitted into Intensive Care and started on chemo, literally straight away.

Exploration

Marilyn and I (Alan) decided that if Naomi did have leukaemia we wanted her to be in a haematology unit where she would get proper care. I remember asking the doctor to transfer her to a proper haematology unit and it taking two and a half days to be arranged. The doctor did not see us during the two and a half days despite the fact that he had seen us everyday
before that. I thought he may have been affronted by my asking to transfer her to the haematology unit. I recall Naomi didn’t like the doctor much because he would not talk directly to her about possible complications and kept addressing Marilyn and me.

When we arrived at the Haematology Unit I remember Naomi’s comment about the drab khaki green and cream colour of the walls saying, “You wouldn’t feel like getting well in a situation like this.” When she was admitted we chose to go public because I knew from experience that being private in the public system meant absolutely nothing and you would not get any different care.

I (Rebekah) remember the specialist taking me aside after Naomi was admitted to hospital and saying ‘if I hadn’t taken her to the doctor she would have died before the weekend was up’. Naomi was going into a coma.

The specialist who came to see us after Naomi was admitted to the Haematology Unit was very up front and told us the situation wasn’t good. I (Rebekah) remember staying with Naomi the first night she was admitted into a four bed ward, with one woman constantly vomiting and another woman who couldn’t control her bowels, so it really stank. I remember Naomi saying, “How am I going to get well?” It was horrible. I thought they probably gave our father a rough time for transferring her to the Haematology Unit. The other hospital was nice and at least she had a room of her own. I thought, how can you expect her to get better? After the initial admission she ended up getting a single room a lot of the time. I used to stay overnight and my mother and I slept in crappy chairs and pull out beds. I believe the nurses on the ward do their best. On her 19th birthday they closed the visiting area so family and friends could have a party.

I (Alan) recall Naomi had a course of chemo, which caused an ulcerated bowel. She was with a lot of older people on the adult ward. One of the first things that Naomi saw was an emaciated woman who was being tube fed. I (Rebekah) remember how Naomi sucked on her McDonalds pickle, when she had been three days without food waiting for a colonoscopy, which kept getting put off. Her not eating for three days was torture for her and she was starving. She went through so much, for example removing her central line that had become infected and having to cut it out because her body had grown into it (Alan). Getting a doctor up to do things was a nightmare, even on the day ward sometimes you would be sitting around for a whole day for a doctor to come and do a half minute procedure (Rebekah).
I (Alan) recall getting the dietician up to complain because they could never get her diet right and she was not eating. The TV was costing a fortune and there was nothing for her to do. She did make some friends with the older patients, because they wanted to mother her, but basically there was nothing. I (Rebekah) also felt there was nothing there to do and my Dad bought a laptop and copied movies to keep Naomi entertained.

Naomi went into remission in the Christmas and New Year but it only lasted a couple of weeks. When she was readmitted she was admitted to the transplant unit because at that time it was closed to transplant patients. She had a single room and free use of TV, which was helpful. She developed mouth ulcers on this admission. I (Alan) know the Children’s Hospital had free TV, video games, the Starlight Room, but this was not available in the adult hospital. My daughter, Rebekah, spent a lot of time at the hospital and would stay with Naomi overnight. Marilyn’s working day was from six to ten in the morning, so she could spend the rest of the day at the hospital with Naomi. It was confusing with a lot of running backwards and forwards in order to be with Naomi. I (Marilyn) often stayed overnight in the hospital, often sleeping in an armchair. If you stayed overnight you didn’t get a meal and we had to rely on Alan to bring food in. We lived on crap and knew where every take away store was located. The only time I (Rebekah) remember that we got a meal was when the nurses organised a breakfast tray when my Mum and I stayed over the last night. A social worker organised for us to have a car parking pass at the same rate as the staff, which helped (Alan).

I (Rebekah) felt some of the doctors weren’t listening. Some of them had problems cannulating her and couldn’t find the vein. We developed a strategy where my Mum would stay in the room and say “You’re not touching her” and I would go and get one of the nurses. A lot of times it was the nurses who stood between the patient and the doctors and would say you don’t have to put up with this. The doctors needed to give the patients a little bit more time for the patients to trust them. They could take 30 seconds longer and find the vein or let the nurses do it.

I (Alan) believe every special day of the year can be covered by Naomi’s cancer. She was diagnosed on our wedding anniversary, Naomi’s birthday was a fortnight later, my birthday three days after that, Christmas which everyone has problems with, they were told she was terminal at Easter and she died two days before Mother’s Day.

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Destination

Being told there was nothing more they could do, and if we had something special to do we should do it now, hit us like a ton of bricks (Alan). I (Rebekah) was angry and frustrated when we were told she was terminal. I wondered at what point do you say you can’t do anything and it’s not curable?

After being told she was terminal I (Alan) remember we decided to organise her 21st birthday party and bring it forward six months. She had a ball. The 21st was a gift for her and people were able to say the things they needed to say. We had a book for people to write in and a cushion for them to write on. We now read the things that people wrote on the cushion.

The family went on a holiday to Tweed Heads so we could get away and spend some time with her and so my Dad could say goodbye (Alan). During the trip up she woke in considerable pain and Marilyn and Rebekah were up with her. I (Alan) was told to go back to bed because there was nothing I could do. We (Rebekah) managed to get a script faxed through from the hospital to a late night chemist. I recall the nights before she had been massaging her legs the whole time. While we were on holidays I (Alan) tried to organise for Naomi to swim with the dolphins at Sea World and being refused made me feel absolutely ropeable, even when I explained the situation, they would not budge.

The early 21st birthday party and the holiday was about Naomi giving us something to remember of her outside of hospital. I (Alan) knew Naomi was in a lot of pain when she came back from the holiday. I (Rebekah) remember shopping with Naomi after we came home from the holiday and Naomi saying her shoulder hurt. Just like when she couldn’t breathe and was having palpitations, something in my head said something is not right. I felt Naomi needed to go home and be taken to the hospital. Naomi wasn’t too happy with me at the time. I remember bringing her home and saying to my Mum she needs to go to hospital. Mum then took Naomi to the hospital.

I (Alan) remember getting a phone call from Marilyn, when I was coming home from work, and hearing a piercing scream in the background. I (Rebekah) also remember ringing the hospital and all I could hear in the background was Naomi crying in agony. Naomi never cried, let alone cried out loud.
I (Alan) remember the Emergency doctors wanting to do all these tests to find out what was causing the shoulder pain. A resident doctor, who had formed a close bond with Naomi, told them they were not to do the tests as she was terminal and was her patient. She had to persist for the Emergency doctors to back off.

I (Alan) recalled Naomi was admitted but not to her normal ward and I believed the staff were petrified because they had a terminal leukaemia patient on the ward. She was transferred to her normal ward the next morning. An old school friend smuggled a joey in under her jumper, which really brightened Naomi’s day and everyone else’s. The staff had to try and keep it quiet from the Manager (Alan). I (Rebekah) think the pain management team thought she didn’t need pain relief because she wouldn’t complain of pain, but as her family we knew she needed relief. I (Alan) think Naomi tried to protect the family from the pain but she couldn’t hide it from Rebekah or her mother.

The night before Naomi died the whole family and friends were there. There was a young boy that Naomi had met in hospital, with aplastic anaemia, who wouldn’t come in to her room because it was family only. We (Alan & Marilyn) both told him to get in there.

The Navy would not release her cousin to say goodbye despite talking to the chaplain, the commander, and the social worker. They said they allowed him to talk ship to shore, which was difficult. I (Alan) don’t think the Navy seemed to understand that they were more brother and sister than cousins. She was having regular doses of morphine for the pain and she wasn’t really with it the whole time. When her cousin spoke on the phone she just mumbled.

The night before she died, Naomi was really weak, but she was still trying to go to the toilet. I (Rebekah) was there with my sister and had helped her to the toilet. She was having hallucinations at the time and was in a lot of pain. We called the nurse to help put her back to bed off the toilet. A nurse came and took her back to the bed and then grabbed her legs and swung her up on the bed. I remember Naomi was crying in pain. Naomi was saying, “Please don’t let her touch me again, please don’t let her hurt me.” I found another nurse and told her if that nurse sets foot into Naomi’s door one more time I was going to knock her off her arse. I told the other nurse that if that nurse was that tired and burnt out she couldn’t give a dying patient one minute to catch her breath, then she should be sent home. From then on two other nurses would come and help my sister.
The next morning the nurses believed that she needed a catheter. They got a resident from another ward who said he couldn’t authorise it because she needed a bag of IV antibiotics to stop infection. I recall the nurse said “Do you really think antibiotics are going to make a difference at this point?” I (Rebekah) thought it was just ridiculous that I had to stand in the room and say my sister’s dying and argue over a catheter being put in because she didn’t have antibiotics. I thought residents that aren’t on the cancer ward need a clue or some common sense.

Naomi’s sister Sarah blames herself because she was not there for the last visible breath, even though her heart had not stopped beating (Alan). I (Alan) felt like a stunned mullet when she died because I never believed that she would die. I remember the words in my head when she was first diagnosed, “I will not fail you,” and Jesus saying Lazarus’s sickness would not result in death. I thought I might have had my head in the sand but I believed that she was not going to die, even though I had been told it was terminal.

After Naomi passed away I (Alan) remember my sister-in-law saying, “We will wash her.” Marilyn and my sister-in-law Margaret washed her. I went numb and couldn’t do it. I wanted to keep her dignity in death. While she was being washed I sat in the foyer. I remember the specialist walking past me and the next thing I remember the specialist was sitting down beside me with his arm round me. There was no one else.
Arlene’s story: Mother of Mathew James

Departure
Mathew was six weeks short of his 16th birthday when he was diagnosed. He had his Year 10 graduation and he looked fine. He was fit and played a lot of sport. The summer he was 15 I remember him cutting back on this sport and sitting around a lot. I thought, you get tired in Year 10 but something niggled in the back of my mind.

Exploration
His treatment included chemotherapy, a stem cell transplant and radiotherapy. The cancer returned three months after radiotherapy and Mathew was told his only option was an unrelated bone marrow transplant, which would have a 15% chance of working, and he would have a lot of problems with graft versus host disease. So, he decided to live as normal as possible for as long as God gave him, this turned out to be 10 months. Because of this the usual apron strings were not cut because he needed me more intensely and for a longer period of time.

I chose for him to be treated in the adult system because he had an old head on young shoulders, although I now believe we would have been treated more as a family in the paediatric system. It was difficult being a nurse who had worked in the hospital and could ask the bigger questions. I wanted to read his pathology results and not have them paraphrased to me, but they didn’t want me to do that. I used to have a stand up fight every time and gave them a hard time. I believe I alienated all these people, although I think maybe what I saw as a barrier wasn’t really occurring and was in my head. The medical staff could never understand why Mathew wanted me to tell them what had happened since the last visit, they always wanted him to tell them and he didn’t want to. He had asked me to be involved so I think that’s how it should have been.

I feel the staff judged me and I was never game enough to ask what the staff expected of me, such as whether I could stay overnight or come in early and have breakfast with Mathew. I would stay with him until he went to sleep and then I would go. This really came to the fore when he was having his stem cell transplant in Sydney. It was the hardest time of the lot because not only did I not know the staff expectations, they also did not know me. I let them know that I was involved with his care and would appreciate being allowed to do things for him. Adults that were being treated at the time often had their partners stay overnight. I felt
because the staff were so young they looked at him as an eighteen year old who shouldn’t have his Mum fiddling with him all the time. There were things I didn’t do that I wanted to. I didn’t find out until near the end of his transplant that he had wanted me to stay overnight, I had thought that he had wanted me to go home and give him his independence and that that was what the staff wanted too. At the same time, I didn’t feel they judged the partners or sons and daughters of the adult patients. At one stage, I realised that if he got better I wouldn’t be needed any more and this made me very upset. Although, I wanted him well.

I had a pathology position, which I wondered if it was a Godsend because it allowed me to take Mathew’s bloods and to connect with him more. It was difficult when I was not allowed to take bloods for the oncology patients anymore, because a colleague had said I was breaking confidentiality. I thought my boss understood that when you have been through the same thing you become like a family and you’re involved in everybody else’s business. This happened at the same time we were told that was it for Mathew, and it was just awful, bad. I was aware that other teenagers were having treatment, but they never seemed to have appointments on the same day that he did. I knew he hated sitting in the waiting room with all the old people. I’ll never forget sitting there one day and this old man came in with a fungating cancer on his neck. Mathew was disgusted. I thought it was too real for him because his was all inside. He wasn’t the sort to talk about his illness but the old men would sit around and talk about their treatment. The one person he had a rapport with was a young woman in her 30s being treated for breast cancer and they used to talk and joke about the love affair with the toilet.

The pastoral care that he and the family received from the school in Years 11 and 12, when he was having treatment, which was just amazing. When he left school, they would still come and visit him at home and they kept in touch wanting to know what was going on. He still stayed connected to the school through his girlfriend and her debut. They were asked the following year to show the next debut class how to dance. Everyone thought he was amazing the way he handled his illness. How he worked to help - and protect other people. When he had made the decision to take the tube out of his lungs and say his goodbyes he said, “I wish it wasn’t now because it is exam time at University and my class mates will be so upset about me. They won’t be able to concentrate properly.”
He wanted to live life to the very end and joked as though he was not dying. He joked about being fried and going out with a bang by dying his hair blue (which he didn’t). He made the decision to stay in hospital, say his goodbyes and then take his chest tube out. His lungs would fill up with fluid and he would be gone in three to four hours. The nurse who was supporting us said she was glad that he had made the decision because it meant he was ready to accept it.

When he went back into hospital he would only go in if he had a private room, because he didn’t want to be looking at the oldies with their fungating growths. A few days later he refused to move for an isolation case, he said he would go home, so he got to keep his room. He asked me to ask his friends to visit and for me to explain to his friends and his girlfriend that it was the end for him. He told me he didn’t want his girlfriend to be there after they had taken the tube out. He would be going downhill really fast and he wanted her last memories to be of him being able to have a conversation and still being able to kiss her and stuff like that. I think his girlfriend believes I pushed her away in the end. I explained to her it was what he wanted. I said she would find another boyfriend but I would never find another son. His girlfriend eventually forgave me and now we are quite good friends.

He had been in hospital for three weeks before he died. I was on a knife’s edge the day he died. They had taken the tube out on the Monday afternoon and he got through to the Tuesday and he wasn’t too bad. He asked to see his girlfriend. His girlfriend upset him because she mentioned friends at school were talking about how he was going to die and he was furious. He was a private person and he didn’t want these strangers talking about him. I calmed him down and said they were talking about him in an, “Isn’t he amazing sort of sense, not in a gossipy sense.” This really upset him and took energy that he didn’t have. I did not sleep a wink for two nights because I kept thinking, ‘What if he dies while I’m asleep?’ I remember the day he died the doctors were coming and going all day and there were people in and out and I got a bit of a second wind and made it through. I thought I was functioning but obviously I wasn’t because people have said they had been there that day and I don’t remember.

My husband arrived at 9 o’clock on the day he died and we sat with him all day. At 3 o’clock we all went to get a coffee and when we came back the nurses offered us a chocolate each. We had a chocolate each and took the coffee back to Mathew’s room, he had a couple of sips and said he was a bit tired and he went to sleep and never woke up again, really. He had a bit
of a shaking reaction at about 6 o’clock and then the struggle with breathing, half a second breathing in and ten seconds breathing out. I had called a good friend, who was a priest, and he came at about 5 or 6 o’clock and sat with us. I had given Mathew permission to go, out loud, and I was thinking ‘Don’t take another breath, please don’t take another breath.’ The time was stretching, then at 10 past 11 I had hold of Mathew’s hand, and I was tired. I lifted his hand and put my head down on the back of his hand and in my head I said, “Dear God, he’s not mine anymore he’s yours.” Then Mathew went, ‘Haah Huh,’ a deep breath in and then out and that was it.

I realised it wasn’t Mathew that needed permission to go but me who needed to let go. Mathew couldn’t have heard me because it was in my head but I believe God was waiting for me to say he’s yours, not mine. It was spooky and the priest had never seen anything like it in his life.

I pressed the buzzer when he died and a nurse he never really got on with came and was really upset and said he was amazing. Everyone told me how amazing he was. I remember my GP advised my daughter and I to have a viewing of the body because the last memory we would have would be of the struggle. When he died I had in my mind the picture of ‘The Scream’. The GP said if I saw him in the funeral parlour, I would see him peaceful and that would be my last memory. I went to the funeral parlour the Monday after he died and had not thought about him being icy cold and I got really upset. I recall going and having a cup of tea and then going back in. I stroked him all over and talked to him. His lips were slightly parted and there was brown stuff on his teeth that looked like dried blood. I realised it was the chocolate from the coffee and the chocolate he had eaten on the day. I recall saying, “I spent a bloody fortune on those teeth, and look at them, they’re covered in chocolate.” This broke the tension. Although when I tell people they can’t see the funny side and think it is a strange thing to be stressing about when you have just laid out your child.
Sue’s story:  Mother of Ben

Departure
I took Ben to the doctor for a very small mole on his back, the doctor had said it was nothing and to come back if it starts to bleed. I remember Ben showing me the mole one night and it had become itchy and was bleeding. We went back to the doctor who said they could scrape the top of the mole and send it away to pathology. By this time I was really worried, so we went to my husband’s (George) doctor who said the mole had to be removed.

Exploration
Ben was referred to a specialist in a major Sydney hospital and within a week he had the mole and the surrounding tissue removed. That’s when they said things don’t look too good. We went back in a few weeks time and he had his whole lymph gland taken out. The specialist was positive and said, “We are going to beat this.” It never occurred to me that my son might die from it. I blame myself because I waited so long to take him to the doctor. I had to practically sit on him to get him to go. I remember once he went to the specialist he was OK to go. I arranged it so that he could go after school and he was able to go to soccer and baseball training or whatever. Every time we went the specialist would say, “OK we’ll take this, we’ll do this or do that.”

After one operation, where Ben was not operated on until 9.30pm at night, he wouldn’t wake up, he had gone into a really deep sleep. It was pouring rain and the middle of winter and I thought how was I going to get him home, everyone had gone home except for 2 or 3 nurses. When he woke up he just wanted to go back to sleep, he then had to have something to eat and get dressed. I apologised to the nurses and said, “You poor things.” They said, “Don’t worry he’s a delight to look after.”

The specialist never really told us he was going to die. I sometimes get a bit angry about that, but how do you tell parents that their child is going to die? The doctors and nursing staff were great and maybe they did tell us and I didn’t want to hear. At one stage maybe they did tell me and George asked the specialist how much longer and the specialist had said maybe six months maybe a year. I believe that I was hanging on for dear life, that they might be able to keep it under control for a year or so and I didn’t want to accept anything else. I didn’t want to accept that I knew he was going to die. He was just starting to become a man and I found that the hardest thing. I felt I had no real support at the time.
I knew that Ben didn’t want to die, he fought and fought, I had never known anyone who could fight as much as he did. In the two years he did everything he could possibly do. The only thing he didn’t do was sit his HSC, he was too sick at that stage. What meant the most to him was being able to see his friends and just enjoy life. I’m now finding out that some of the things he did were amazing.

I believe Ben was angry. I found something he wrote in his school bag for the HSC which said, he blamed his parents, he blamed the system, he blamed the doctors, and why did this happen to him? I wondered if this is true, or was he just writing it as an essay? It plays on my mind and I torture myself when I read it. He went through the surgery and he would tell his friends that the scars were from shark bites, especially the girls. That was the sense of humour he had. His sister (Erin) shaved his hair and I couldn’t watch. I had to go outside, he had such beautiful red hair. His attitude was, look no more hair, he said, “It’ll grow back.”

During this time I remember him having a liver biopsy, which was very painful. This was on the same day my daughter graduated from university. Ben didn’t want to see anyone because he had to lay still for four hours, which was very hard. I recalled them saying everything was fine, there was a spot but it wasn’t doing anything. He was interviewed by 60 Minutes [a TV program] and that was when I realised how mature and brave he was. He had no problem showing his face and his scar and was very mature about the cancer. I felt very proud of him. People would come up to him and tell him he was fantastic and brave. I can’t watch the second interview because he almost said he was going to die. He never lost hope and he fought and fought. He took his medication without problems. I believe he coped better than I would with the amount of pain he went through. Except for the three major operations he had, most things were done under local anaesthetic.

I remember one time Ben asked the specialist if he could put off taking his gland out for a week. He had wanted to go on a Venturers camp to the mountains. He did the Dragon Skin for four days in the bush and I worried myself sick but he came out fine at the end. He had a ball; he loved it. I saw photos later of the places they went and the places they crawled and I was glad I didn’t know about what he was doing because I would have had heart failure. I think the specialist probably realised that these were the things he had to do.
When Ben had the gland done he had a drain in it and it started to leak, this was on Boxing Day. The District Nurse had come to keep an eye on it and she wasn’t due to come for a couple of days. We went to the Emergency Department and he was admitted to the paediatric ward. I remember a little girl was running all over the place and they had some stupid kid’s video going and I thought I was nearly going to go mad waiting for the doctor to arrive. Poor Ben had towels to stop the leaking and it was leaking badly. He was saying, “I wish they would hurry up, I want to go home and do things.” A doctor eventually came and patched things up. The doctor wouldn’t take the drain out because Ben wasn’t one of his patients. It was all a bit of a worry.

At the end of 2005 Ben started to complain of a backache. They did a CT scan and X-ray and the specialist said there was a tumour on his spinal cord. I remember the specialist said, “We’ll just leave it, it’s not going anywhere.” He had check-ups after that but the one on his back got worse. Around Christmas time he was in a lot of pain. There was no one open, there was nothing, I was going all over the place. We went back to the hospital the day after Boxing Day and waited for six hours. He was finally admitted. He was admitted to the oncology ward, which just threw us, even the word oncology makes me sick. I dreaded him going into a ward with old people, but he was next to a young boy who also had cancer and they had their Play Stations. The young doctor on duty said they couldn’t do anything, they had to get hold of the specialist. The next day he had an MRI. The staff were really good. The nurse who looked after him was a transvestite and couldn’t do enough for him. He had an operation to take out the tumour and they put rods in his back. He complained bitterly about the hospital food. His mates would bring him books and things but he wasn’t interested in reading. By that time he probably realised he was going to die.

**Destination**

Ben came home and sort of went downhill from there. There is another part to the story. My youngest daughter, Kellie Anne, fell off a balcony in Brazil during Carnivale. I remember sitting on the stairs and screaming, “I don’t know what to do.” I knew I had to stay with Ben and that every minute was precious with him. My second daughter ended up going over to Brazil to bring her home.

On Ben’s birthday ten friends landed on the back door step with a cake and present. By that time Ben was going into a coma. His friends were just amazing, they couldn’t do enough for him. They took him to hospital and he was in a wheelchair and still sort of lucid. I explained
that we were there to see the specialist. I then heard the guy say, “Oh it’s terminal” and I thought I can’t deal with this, I don’t know what to do.

I remember waiting in the Emergency Department for hours and hours and Ben kept drifting off to sleep. He was admitted and they put him in a horrible ward off the oncology ward, it was dreadful. It was a room with four beds in there, all old. They were going to do another CT scan so we waited in the ward until 8.30 pm and they didn’t come back to see us. I found a nurse and asked, “What are you going to do with my son?” I was told they couldn’t do anything that night and we’d have to wait until the morning. I recall coming back the next morning and Ben having the CT scan. We were told it had spread and it was heading to his brain. I was sitting in a room with the specialist and other people who I didn’t know. It was like people talking. My head knew what was going to happen but my heart didn’t want to believe it. We were told all we could do was keep him comfortable and to take it day by day. He was put in a room on his own which was horrendous, the colour of the walls made me sick, the paint was peeling.

He rallied and it was suggested that they transfer him to a hospice, which was only 15 minutes away. I recall Ben saying, “I’m not going there I won’t come home.” He fought hard and the doctors were amazed with him. He came out of his coma and couldn’t wait to come home, he hated being there and he came home. Ben never lost hope; he just fought and fought. Ben came home and he had a fall about two days later. I remember one epileptic seizure he had when he was home, he went blue and got himself wedged between the bed and his chest of drawers and I was trying to get him out. It was frightening, my sister is an epileptic and I had seen it before, but when it’s your own it is horrendous, and you’re powerless, you can’t do anything.

I knew I couldn’t look after him and he would have to go to the hospice. He was taller than me and at that time my husband was sinking deeper and deeper into depression and I knew I couldn’t depend on him. I remember going to the hospice and the people there were just so caring and like angels. He had a private room that was just so bright and overlooked Botany Bay. They then moved him into another room, which was even more special; the nurse told me they only put special people in that room. The nurse told me that that even now when they walk in there, there is an aura about it; I would like to believe that.
We made the hospice room our own, with a banner CanTeen members had made him and photos his friends brought in. His friends would come and visit any time of the day or night. I think Ben didn’t realise that his friends would stay until the end. It is a big thing to ask a 17 to 18 year old to go and see a mate who may not live until the end of the week. Some would come and sit quietly for a while, while others were noisy. The staff at the Hospice thought it was fantastic that there was laughter in a place like this. The staff told me that they had never had anyone as young as Ben in there, never. There is nowhere for kids with cancer to go.

By this time Kerrie Anne was home and in hospital and my husband, George, had been admitted to the psychiatric unit. I remember when Ben was in the hospice I rang George at home and he couldn’t talk. I went home and saw what he was like. I felt I should be home looking after him but I couldn’t because I needed to be with Ben. I asked a neighbour to take him to the hospital. He was admitted and was like a zombie for three weeks, they had him very dosed up.

I was going between Ben, Kellie Anne and George. I knew I had to do it. I couldn’t leave Ben; something was driving me constantly. I would be back in an hour. Visiting George on the secure ward really got to me. My visits were very, very short; there was no conversation, nothing. I would tell him about Ben, I don’t know if it made it worse but I had to let him know what was happening. I knew I had to get Kerri Anne over to see him and that was very hard to witness. Kerri Anne kept asking him if he was going to die and he was tired and I was thinking this is just too much. He said, “Oh Kerrie Anne of course I’m not going to die, I’m not going to die.”

I think I got through because Ben never complained. No matter how much pain, no matter what he was feeling, he never said ‘why me?’ He never said anything about dying, even when it was just him and me in hospital. I think maybe he was trying to spare me because of the other things that were happening in our lives. Unlike my aunt who organised everything when she died, there was nothing like that. He never said, “Mum, I know I’m going to die and I want you to do this.” He didn’t have the chance to do any of that. I was left to try and think what are we going to do with him. I hope to God that he knew I was there for him. It was very hard. Every now and then I have this horrible feeling that I could have done more or said more but I don’t know. I know he loved us. I questioned why me as a mother couldn’t save him. I believe mothers have an instinct, why can’t they save their children? But it’s an insidious disease and there is nothing that can be done.
I kept thinking Ben was so strong. If he had lived he would have been a fantastic male later on.
I wished I had documented things because I wanted to look back and say to him “This is what
happened on this day, do you remember that?” But it was just one disaster after another and I
didn’t have time.

I recall the CanTeen banner falling off the wall about an hour and a half before he died. I
thought, ‘that’s strange.’ At that stage I contacted my daughters and my mother and sister.
George was still in hospital and couldn’t come, he wanted to remember Ben the way he was.
There were helicopters all around. Ben had a thing about helicopters, he was going to have a
helicopter ride for his 18th birthday but he was too sick. Every time I see a helicopter now I
think Ben’s up there flying around.

Ben was not in pain, they were giving him morphine. The social worker asked me if I was okay.
I asked what was going to happen, because I didn’t know what to do. The social worker took
me to the lounge for five minutes and when I went back he had died. I can’t forgive myself
because I meant to be there when he died. I had been there every minute and he did not
wake up, he just went to sleep, he was not in pain but that makes no difference. The staff
rallied around and talked me through what we had to do; I was in shock and didn’t know.

When Ben died I knew I couldn’t deal with George. I was terrified of what it was going to do to
him, push him completely over the edge. The doctors and the nurse sat George down and told
George that Ben had died. I wanted them to tell him. I needed him. I went to see George that
afternoon and said he had to see Ben. The funeral parlour sent a car to pick us up. George
was able to say goodbye and he was lucid and okay. We had to decide what clothes Ben was
going to wear and I decided on his Venturer uniform. Ben looked very peaceful and very calm
and it was very, very hard. I just wanted to pick him up.
Lauren’s story: Sister of Grant

Departure
The first sign that something was wrong with Grant was when his left eye started to look a bit puffy and bulging. He was a ‘tradey’ so we thought that he may have got something in his eye. He went to a local GP who found nothing in his eye, gave him some drops and said it would get better. I noticed that within a week the eye got worse so Grant’s local GP referred him to the Eye Clinic at the major public hospital. Mum took Grant to the hospital in the morning and she called me that afternoon from the hospital, initially I thought my Mum’s car had been stolen and it did not even occur to me that there was something wrong with Grant. I asked my Mum what was wrong. Mum said Grant had a tumour. I started crying and asked, “How can they just say he has a tumour?” It was unbelievable. My mother told me that he had had a CT scan to confirm the tumour. I called my Dad and blurted out, “Grant’s got a tumour” without even thinking how it would impact on him.

I remember going to the hospital that day and seeing Grant after a nose biopsy, which was horrible. Grant was leaning over a kidney dish with blood coming out of his nose. He was emotional, and I felt he was vulnerable and troubled. I went out into the hallway to cry because I didn’t want to cry in front of Grant. A nurse came up and told me to stop crying, to stop being a baby, that there was no need to cry. I remember thinking, ‘What would you know? It is not your brother in there.’

After that, he was referred to an ENT specialist, as the tumour had started in his sinus cavity. I remember the specialist talking to my Mum and Grant first. Then the specialist spoke to me and my stepmother and told us what I believe was the real story, of the possible side effects from radiation, such as losing his vision and seizures. I assumed that the specialist, as a professional, thought my Mum and Grant could not handle the information at the time. From that point on I felt burdened by responsibility. I felt myself, and my family, were supported by the treating team from them on.

Exploration
Grant had chemotherapy immediately, to shrink the tumour. He was treated in an old ward, which was dodgy it was an old, old, old tile house and it was a really dark, dingy ward. Grant swore it was haunted; it was so gross. Grant was really sick with the chemotherapy and we nearly lost him a couple of times. He was in hospital for most of the time and it was pretty full
on. The care Grant received while in hospital was holistic, with many specialist teams caring for him such as the acute pain team, neurology team, the oncology team and the dietician. There was always someone there to make sure he was getting the best care. The nurses were very supportive and considered not just Grant’s needs, but the whole family. They opened up the ward and their hearts to us.

Grant being in a ward with oldies was not nice, some of the patients being in the last stage of cancer. Grant wouldn’t complain, he would try to make the most of it and just laugh it off. When they were coughing and swearing and getting around like old guys do, he would kind of pull faces. It wasn’t the most comfortable situation and he was probably lonely. He was always treated as an adult in the adult system.

It was during this time that I recall researching support groups for young people living with cancer and coming across CanTeen and we both became members.

The tumour was shrinking because of the chemotherapy, and the treating team started radiation and chemotherapy together, but he got even sicker from the radiation and they had to stop it.

**Anticipation**

After six months of treatment with two lots of chemotherapy and the radiation, I remember being told that if the tumour had not re-occurred in five years he would be cured. The treating team believed there was a great chance Grant was cured. We were told of the possible long-term side effects of the radiation treatment but that was further down the track and for now Grant wanted to just live life. Grant and I had decided to get a tattoo together, when the treatment was over, as a reminder of what he had been through and that he was going to survive. I got the tattoo the week we were told he would probably survive but Grant was too weak to get one at that time. That week was a pretty big exciting week.

**Destination**

Grant didn’t seem to be getting any better and was still weak and unwell. It was devastating when he started coughing five months later and they found the tumours in his lung. I recall being told he would not live and asking lots of questions about our options. I remember the sunken look on Grant’s face and all of the family crying when he was told he had less than two years to live. It sunk in that he was going to die.
The experience was different this time. The first time, no matter how challenging, there was always a light at the end of the tunnel. It didn’t matter how sick Grant got with treatment because in the end he would be alive. The family thought he would get better and he was determined to survive. This time, even though they were giving him the best treatment they could, while they could, it was like the medical profession had given up on him in a way. The quality of care didn’t change, but the focus of care changed, they would make him sick enough so he could be well enough for a while. The emphasis was more on the quality of life for him. The treating doctor wanted him to have dignity and a sense of peace and enjoy what time he had left. The medical profession didn’t treat him as a possibility; it was more a matter of when he died, and how to make from now until when he dies better. The fact that there was nothing more they could do felt horrible.

I noticed that with this changed focus of care the treating doctor demonstrated more compassion. You could see the pain on his face. I think he probably gave a lot of emotional time to the family.

At this time we looked into alternative therapies that we thought might help. At the end of the day the tumour was just too aggressive. Because rhabdomyosarcoma was a rare cancer, there didn’t seem to be a clear understanding of it and everything we did was kind of experimental; there were no set protocols like for leukaemia and Hodgkin’s lymphoma. Despite being told he was going to die Grant and the family never gave up hope. I think we did not really want to accept it; it was too hard.

Grant gave me Power of Attorney for his Health Directive and I was able to make decisions based on the guidelines he had set out for me. I knew him, how he was and when he was getting worse. For example, I had to advocate for him to have a chest X-ray the week before he died. The doctors were going to send him home. I felt his lungs were full of fluid, even though they had been drained a day and a half ago. The doctors thought he could go a couple of weeks without the lungs being drained. The X-ray showed his lungs were full of fluid and needed to be drained again. The doctors sort of went, “Whoa, after a day and a half and he needs his lungs drained again.”

I was probably more responsible for Grant’s care. The doctors would call me if they had a problem and it would be me asking the questions. My Mum would go with the flow, my Dad
would distance himself and Grant went with the flow his entire life. I was always the one standing up. It was hard being responsible, but it had always been that way, he was my little brother and I had looked after him my entire life. My role expanded by doing a lot of the home stuff like cooking, cleaning and shopping, trying to study and work, be Vice President of CanTeen and also be there for Grant as much as possible. I believe I was a support for my Mum, knowing it was my Mum who had to care for Grant. I was also the backup for Mum if she couldn’t be at the hospital. As long as I helped, it helped my Mum.

I think Mum was at times overwhelmed with the medical information. Due to my interest in the medical field, I was able to break down the medical information and understand it, despite my emotions. Because of this, there were times when I had to assertively try and convince my Mum of the truth of the situation. This was horrible and I felt like I was breaking my Mother’s heart but she needed to know the truth.

I know I was pretty needy a lot of the time and it was Grant who probably comforted me during that time. He was my strength; he was my support even though he was dying. He supported me by hugging me, by telling me I was doing the right thing, listening to me, letting me cry and telling me it was OK to cry. He told me he liked it that I cried. I felt that he was trying to be strong for everyone and everyone was trying to be strong for him and by me crying he was saying let’s get down and be honest. I think he liked being able to take care of me emotionally as I was caring for him physically. He would just listen to me and assure me he was not giving up and that he was OK. His arms were so skinny but he could still give me a hug, I could feel his heart. He never really spoke much about his feelings and tended to bottle it up while I would cry. He never complained and just took things in his stride, he would say, “All right we just have to do it.”

His strength didn’t decline gradually, it was like one minute he was running around the block and the next minute he needs help with everything. His daily care increased and his strength decreased the entire time, so he needed a lot of help.

A few days before he died I had a panic attack. Grant was surrounded by the extended family and he was asking people what was going on with them. He was in so much pain he couldn’t even laugh when they said something funny and it was horrible to see. They were trying to be supportive and their hearts were in the right place. They probably wanted to spend some time with him but it was harder for Grant and my Mum and Dad having them there. It was
exhausting. All these people were there and I didn’t want them there, I just wanted to be with Grant and relax and for everyone to be able to relax with him. Everything went blurry and hazy. I had to leave the room quickly as I didn’t want my Mum to see me like that. I left and collapsed outside the nurses’ station, I was burning up and the nurses got ice towels to put on me. I guessed I was hyperventilating and couldn’t breathe, I was crying and the feeling was horrible. Then Dad and I went for a walk in the park until I felt better. I think the attack occurred because I just needed to release the stress. At that time there weren’t a lot of tears, there weren’t a lot of outlets, it was just dealing with every second of the day and going through the process, we were just surviving. I came back to the hospital room when the family were leaving and I recall sleeping on the bed for a few hours, when I woke up I felt I could deal with it all again.

On the day Grant died I didn’t want to accept it because we had been told so many times he was not going to make it and to say your goodbyes but he always pulled through. I was at a CanTeen function and didn’t have my phone on me, when I checked the phone there were twelve missed calls from my Mum. When I rang Mum, she said you have to come to the hospital right now as he might not live an hour. I spent the night in the hospital and he made it through the night so I thought everything is fine. I remember Mum saying, “Don’t leave the room, don’t make a cup of coffee, don’t leave.” I was thinking he’s going to be fine it is just like before. One of the nurses told us he could be like this for another two weeks.

I remember how distressed he was that day; I don’t think he was in pain as they had him on so much morphine. He said to the nurses that morning he didn’t want his family to worry. After he said that, I said to him, “I’m not leaving you when you are ready to go I will be right here with you.” I remember Dad speaking to him and saying the same sort of thing as I had, such as we love you and when you’re ready you can go. The only other thing he said that day was to look up at a nurse and say, “Thank you for everything.” I remember thinking, it would be better if he died, as he wasn’t living, he was existing and suffering. It was in the afternoon that a nurse told us he would die within the hour and it hit me how Grant had been for most of the day; that it was really happening and I could not, not want it to happen. Mum just burst into tears and about 10 minutes later she told him it was OK to go.

I felt waiting for him to die was kind of morbid because each breath was so far apart and so slight and we weren’t sure when he stopped, because we would think that was a breath. I remember he kind of took this little gasp and we were waiting, waiting and waiting and
another one didn’t come. I just started crying. After he died the nurses were great, they gave the us a few minutes with him and hugged us. My family were too overcome with their own grief so we couldn’t hug each other. It was weird; we went into the next room and started calling all these people to tell them Grant had gone, I felt it was because we had to do something.

The compassion of the nurses was wonderful. After the nurses had cared for his body they let the family have as much time as we needed with him, they were there if we needed them and they just let the family do their own thing. Mum was the first to leave Grant, I think she didn’t really want to leave, my Dad left next. I think I had the hardest time leaving and I realised it was time to go when he started not looking like himself and I didn’t want to keep seeing him like that. I hugged him and walked out.

That night I had a dream where I was laying in the bed in the room he died in, he was in his chair and he got up and walked out of the room, there was a bright light outside and he looked back and gave me this big cheesy grin, waved and walked out. The dream gave me a lot of peace at the time because I thought it was him telling me he was OK.
Shane and Andrea’s story: Father and Stepmother of Grant

Departure
Grant looked like he had something in his left eye, which was watering and sore. I (Shane) suggested that he go to the doctor. He went to the doctor and initially the doctor said there was nothing in it. Grant then went to another doctor who also thought there was nothing in it but decided to send him to the hospital for tests and they found the cancer. We were able to get him to have an MRI scan that day. It was a real shock to think he had cancer and not knowing if it was curable or not.

Grant was referred to an ENT specialist who said the tumour was inoperable at that particular point in time, because it was too big and that he would have chemotherapy and radiation, which the ENT specialist said he would organise. I (Andrea) started getting worried because Grant seemed to be going downhill from that point on so I rang the ENT specialist and said, “I think he is dying in front of my eyes.” The ENT specialist said he was trying to do the best he could and he organised the treatment team and decided with the multidisciplinary team the best form of treatment. They decided it was chemotherapy first and then radiation.

Exploration
The doctors had told Grant he would have three weeks to live if he didn’t have treatment. The initial treatment almost killed him. The oncologist called us in one night when they thought he was going to die that night. I (Shane) was a mess. Grant broke through and he seemed to get stronger after that.

Treatment was a roller coaster ride, you would think everything was going well and then all of a sudden Grant’s bloods were out of whack and he’d be back in hospital. As soon as his temperature went out of whack he would be back in hospital. I would go to work and ask for next week off because I wanted to take Grant somewhere and then have to say he was back in hospital. It was embarrassing in a way to say, “Oh he’s good, oh he’s bad.” That was challenging and tiring. You would try and grab the opportunity to drop everything and just go but you were always on the edge of your seat ... plans out the window if he was back in hospital (Shane). We (Andrea) were meant to be going away on holidays at one point when Grant was having some chemo and he got very sick and it was touch and go as to whether we would keep going with our trip. Going through these ups and downs was terrible, feeling this
one minute and feeling that the next, and thinking, ‘Oh my God how much longer can this go
on for?’

The treating team were sort of like family in that they cared so much for Grant, they gave us
the feeling he was special. They all seemed to take him under their wing. The doctors were
the best and they took time out for Grant, nothing was too much trouble. One doctor rang up
in the middle of a football game to see that Grant was alright and came in on Easter Sunday,
after giving Easter eggs to his own kids, to see Grant.

Grant had a dry humour and would make cheeky smart arsed comments. The fact that he
never complained might have also helped. Grant’s friends dropped him straight away once he
had cancer; I (Shane) think they didn’t know how to deal with it at that age, they were just kids
really.

I (Shane) recall the old cancer ward in the public system, death and destruction was my word
for it; although we had the best of care there and could come and go as we wished. He was in
a room by himself and he didn’t have anyone to talk to, if they could have had something for
kids going through the same stuff it would have been beneficial. I (Andrea) think Grant was a
bit of a loner kid and maybe if there had have been something there he might have opened up
a bit more. I believe if it was a more outgoing kid put in the same scenario they would have
struggled. There was also no interaction with any other families.

We were always at the hospital, as a family and we were always talking or playing board
games. We donated a TV and DVD player, it was in Grant’s room initially but it just stayed
there. The DVDs available were all old movies. I (Andrea) think that access to computer
games would be good for adolescents because it would keep their minds occupied and if you
are busy it might take your mind off the nausea. I also thought that if there was an adolescent
unit you could mix with other young people and you would not just be lying there having
treatment, rather than living. CanTeen was a huge help for Grant and his sister Lauren,
without that there appeared to be no services for a young person with cancer.

There is a lot of isolation surrounding having a young person with cancer. There were four
other young people with rhabdomyosarcoma at the time who I think were all being treated in
different places. There was one lad that was keen to meet with Grant but their treatment and
sickness and wellness sort of thing never seemed to fit. I think they would have liked to talk to
each other in their own environment. I (Shane) think it would have been good for Grant’s
mother to have contact with other families with a young person with cancer, because she was on her own and was up at the hospital all the time and to have a coffee with another mum probably would have been nice. Although, we all cared for Grant and it was about being a family to the exclusion of others, we all got on well and enjoyed each other company.

We (Shane and Andrea) thought that from day one we were going to lose him. The doctors were saying the same thing, not in black and white, but if you listened they were saying that he wasn’t going to survive. I (Andrea) just felt it was not going to be a rosy outcome and didn’t want to build up false expectations.

**Anticipation**

After the initial chemotherapy they gave us a lot of hope. We thought he was cured and that he was in remission and the cancer had gone. So I (Shane) couldn’t understand when he was supposed to be well but did not have any energy. We were frightened that he had fought the fight and had now gone into depression. I was really scared that there was no strength left in him and he had fallen into a deep hole, so I kept trying to motivate him along. He then developed a cough and the doctor did a chest X-ray and hey presto, it had disseminated into his lungs. So we were back on the roller coaster ride again but this time we knew.

**Destination**

It was a shock for Grant when he found out he was going to die because he said, “What are you trying to tell me, are you trying to tell me I’m dying, that I’m going to die?” I think Grant knew but he didn’t like the word terminal, but he didn’t mind incurable, he felt that there was a difference.

The medical staff were great, we couldn’t thank them enough, every one of them was amazing, they couldn’t do enough. We were clutching at straws giving Grant a shot at different treatments, such as female hormones. His mother tried natural remedies, which I (Andrea) believed were no help whatsoever. Although, I (Shane) believe that his mother using natural remedies meant that when Grant died, in her heart of hearts, she knew she had done all she could for her boy.

Grant was so brave, he planned his own funeral and picked the place where he wanted his ashes to be. He never complained. One of the last things he said was, “I’m sorry for the trouble I’ve caused.” I (Shane) think he was more worried about his Mum and his sister and
wasn’t too much worried about himself. His mother was very strong, she looked after him so well, she was at the hospital 24/7. I admired her for just being able to keep going, she had one of these chairs - a recliner - and she’d sleep in it. I didn’t have the strength to do that; I would go up there for a few hours before going to sleep. It was easier for me because I had my work and could escape a bit because your mind is off it a lot of the time. Lauren (Grant’s sister) supported her mother with the cooking and cleaning.

I (Andrea) believe Lauren had to escape sometimes because the situation was claustrophobic. She gave up blocks of her university studies. She would say to Grant, “I want to go to a party” and he would say, “Go.” She would then feel guilty and come and ask me and I would say, “You still have your life, you still need to enjoy life.” I think now that Lauren might be thinking she should have spent more time with him and cherished each and every second now that he is gone. But that is not realistic, it is more realistic to think you did your best. You have to forgive yourself and move forward.

Grant and his cancer bonded the extended family together; my (Andrea) family and my ex-husband’s family. They all fell in love with Grant and took him and his cancer on board. There was no disharmony; he was the bridge builder. It was fortunate that my son Matt was able to come and be with the family until Grant died, for about five months, because it was the wet season and he was a jackaroo. There was always good luck with the bad. I (Shane) view the family as being spokes in a wheel, each member would have their spoke out of the hub of the wheel to form another family.

The nursing staff really cared for Lauren when she sort of lost it one day; everything else was dropped. The other nursing staff looked after one of the nurse’s duties and she just consoled Lauren.

Myself (Shane), his mother and sister were with him at the end because we had been told we could only have a couple with him and unfortunately Andrea missed out on being there for his last breath. I (Andrea) felt cheated because Shane never took me aside to tell me that I would never see Grant again. I (Shane) didn’t really make it plain enough and it was a blasé comment like, “You had better say goodbye.” I (Andrea) did give him a kiss and say, “I love you I’ll see you when I come back,” and that was it.
I (Shane) remember how hard the last hour was. In the end I was begging the doctor to give him more medication and he said, “Yeah all right.” Grant was in pain and he couldn’t breathe. It was killing me to watch it so I went out to the nurse and said we need to let him go. Before he went he apologised to the nurses and said goodbye to us, and that was it.
Cheryl’s story: Mother of Paul Malcolm

Paul’s story was so huge because it was a very public, community thing, which I think probably mitigated a lot of things that weren’t happening in terms of support from the hospital.

Paul was a premature baby with lots of problems but he was also a gifted child, this made parenting a little bit difficult. This was made more difficult because I was a single parent with no social support.

**Departure**

I remember Paul had a headache but he didn’t say anything for five weeks. We decided to go to the doctor who prescribed headache tablets and told him to come back. When he came back a week later a different doctor chewed him off for a scan. After the scan I think Paul knew something big was up because of the way the technicians didn’t say anything. He went back to the doctor who organised for him to go into hospital and have surgery the next day.

He was in neurosurgical intensive care after surgery. The next closest in age to him was a man in his early 30s who had a massive brain injury from a horrific car accident and used to wander so it was also a locked ward. The neurosurgical ward was very functional, it was all about the surgery.

Paul had a growth the size of a golf ball in his head and they didn’t know if it was benign or malignant. It turned out he had glioblastoma, which is a very aggressive brain tumour that spreads at a microscopic level. They said there was not much they could do and that he had six months to two years to live and they were very, very sorry. I felt the diagnosis was unrealistic because people had always said Paul was a mighty man of God, head and shoulders above the rest.

**Exploration**

The surgery was extensive and they needed to excise a lot because of the kind of tumour. Because of this they were not sure of the effect the surgery would have on him. Paul then had radiation, the maximum dose he could have. During this time he would go to school when he could. He was pleased with himself because he could show off his radical scar. He missed an awful lot of school and yet he still passed Year 12 posthumously, based on the work he had done earlier in the year. He was an amazing young man. When he returned to school he
would have fits as a result of the surgery. In the end the fits caused him more distress than the
cancer, the surgery and the radiation. He got to a point where he knew what they were and
was able to manage them. Later in the year he was getting a metallic taste in his mouth before
the fit. This was a signal to me that the cancer had spread. I was not sure if he knew it was
growing as we were just trying to get on with life and he was very much thinking into the
future.

During Paul’s treatment I had one foot in two camps, the reality of what God can do and the
reality of the medical diagnosis. It was very difficult to stay in either reality. Throughout his
treatment I tried to stay with what Paul wanted, which was to be healed and to glorify God. He
was a recognised leader and had great leadership potential. He also had a gift with children; if
you went into a room full of children you wouldn’t see Paul because he would be underneath
the children. The day after he had had major surgery he was discharged from hospital and he
went on a leadership camp. He continued with the leadership mantle right through treatment.

Whilst Paul was in hospital there was someone with him all the time and people were wanting
to see him and practice their healing on him. I recall one teacher who felt he had to come in at
4 am to massage his feet when Paul was having a rough night and wanted someone to
massage his feet. There were things like that happening all the time. I didn’t expect him to go
downhill so quickly and we never really got to plan a lot. There was a lot of information that I
didn’t understand medically and there wasn’t time to take it on board. I would juggle what I
heard medically with what I was hearing spiritually. There was a group of intercessors that got
around Paul and were doing a lot of prayer stuff, which I did sort of understand. The downside
of having so many people around was that we didn’t really get any private time together.

The whole Christian community of Hobart supported the family; it was cross-denominational
and even included people I didn’t know. It is expensive to have kids in hospital and the
community helped. The school principal wasn’t coping with the idea of a kid with cancer. The
first time he visited he stood at the door, after the second visit he came and spent some time
at the bedside.

It was never obvious that Paul would die. I knew nothing about this cancer and was
dependent on what the medical people were telling me and there appeared to be a divide
between the oncology and surgical medical people. Paul was getting sicker and sicker and was
very frail. He was on the oncology ward and was going to be given an experimental drug from
America, which had limited release on compassionate grounds, but there were delays in getting it. Paul deteriorated so quickly that permission was withdrawn when the drug arrived. There was also a point where there was a possibility of experimental surgery in Sydney, but I felt we would lose the support and there was no guarantee that anything would happen. It probably wouldn’t have worked because of where the tumour was situated. The tumour had spread to the Sylvian Ridge, which is where speech, sight and all those sort of things are so we decided not to do the surgery. The oncology doctors told me there were things they could have done if they had seen Paul earlier. He became deaf and blind and very frail and we had to shout to communicate with him, which was difficult for other people on the ward, but what else do you do? This was my son; I had to communicate with him.

I noticed the difference between surgery and oncology. When he was in surgery it was very functional and quick and a shorter stay. It was about the surgery. When he was in oncology it was a longer stay and he was becoming sicker and sicker. Paul was still having a lot of visitors, someone was always with him and because of this I didn’t get to talk to him about stuff, which is a shame. I think that if he had have been on a ward with people more his age he may have been more comfortable. Despite things going very wrong I realised that by the time he died he was hearing and seeing, not completely, but certainly enough for the nursing staff to say, “Paul we’re here.” The nurses used to come and do things with him without talking to him and would say things over him. They said things that they never would have said if they knew he was seeing and hearing. I remembered he changed what he was doing a few days before he died. I remember him turning his head towards a teacher in the room as evidence that he was hearing and seeing. This was not possible as he had nerve damage.

I was also caring for my other two children. My daughter was having problems at school because of all the scuttlebutt that was happening at school. At one stage when he was really really sick a particular girl at school said that Paul had died. His sister appointed a spokesperson who would answer any questions about Paul. Cheryl didn’t really know the extent of what was happening until after Paul died. It was just so overwhelming.

**Destination**

I could not understand why the visions that God was giving me were so different to what was actually happening to Paul. A couple of days before he died I knew he was going to die on the Thursday. I believe that Paul was prepared for it all the way through and secure in where he was going. He was so sick that either way would have been a relief.
Paul had been moved to the surgical ward to a side room near the nurse’s station. On the day he died every now and then he looked past my shoulder. I had prayed for angels in the corner of the room and I believe he was looking over my shoulder at the angels. Before he died I remember seeing his spirit leave his body although, he continued breathing for another ten minutes. I saw his spirit around the ceiling somewhere, looking down on his body. I was aware that this person in the bed was not Paul and it was no longer a person. I believe this to be a knowing kind of vision. I felt comfort that his soul had gone and have absolutely no doubt where my son is. His death was confusing because we had expected him to be healed and I believed there had been a gradual progression in his healing with his sight and hearing. The healing was beginning to happen. When he died I prophesied over him that in three months there would be breakthrough with this type of cancer. I believe there have been news items that suggest this has happened.