The experience of dying: a reflective topical autobiography

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THE EXPERIENCE OF DYING: A REFLECTIVE TOPICAL AUTOBIOGRAPHY

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

February 2008
STATEMENT OF SOURCES

I, Carmen Zammit, declare 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.

Signed ..................................................    Date ...........................................
DEDICATION

This work is dedicated to Michael
ABSTRACT

This thesis aimed primarily to describe my experience of dying. A second consideration was to describe the impact on family, friends and others. My initial objective was to write down my experiences in response to the many questions and concerns raised by family members and friends. I believed they were interested in making more informed decisions about their lives and treatments should they themselves be diagnosed with a life-threatening illness. I wanted to give a true account and accurate information, which in the first instance might help my own genetic family. Beyond this, I hoped to reach those interested parties, who would benefit from this information and knowledge, particularly those who themselves were diagnosed with a life-threatening illness, and those at risk of doing so. My hope was that it would also help their partners and carers, both personal and professional, to also know and understand the experience, so that they could give the support that comes from knowledge and empathy.

This Reflective Topical Autobiography (RTA) comprises a trajectory of events and reflections, documented chronologically, to capture the detail of my life journey, in relation to my cancer diagnosis. The images and stories portraying my life journey with cancer include works entitled: Origins, My Family, My Culture, Rag Doll, The Demon Within, The Silent Scream, The Fighter, Feather Inscape, Slipping Away, Living Horror, Mother, Morphine, Heart of Peace, Living in the Shadows, Cancer (Mis)information, and Withdrawing/Emerging. Accompanying reflections provide insights into the creation of the images and how I have come to interpret them and make sense of my experience of dying.

This RTA fulfils most or all of these aims and objectives, some of which can only be realised over time, as people resonate with my work and personal insights into what it is to experience dying, as an immediate and ever present reality.


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CHAPTER 1 INTRODUCTION

This chapter introduces the thesis with some preliminary comments on the process of dying, to set the foundation for the significance, aim, objectives and background of this Reflective Topical Autobiography (RTA) of my experience of dying.

The process of dying is an undeniable life stage we must all inevitably experience. Living through life-threatening illness to the point of near death has made profound and positive changes in peoples’ lives (Bartholome cited in Byock 2000, p.281; Foos-Graber 1989; Longaker 1997; Remen 1996; Carrie cited in Sandstrom 2003, p.470; Weekes cited in Zammit 2001), including my own. It is possible to make these changes before our own death. The information contained in this thesis shows that we can consciously choose how to take leave of our present reality, the people we so love, and this wonderful and unique planet. In discovering how much we have to lose, we may equally begin to realise how much there is to love in our life, now, while we still can.

Much work has been done to describe the process of dying from the point of view of physicians, nurses, psychosocial and medical researchers (Bourgeois et al. 2004; Chan 2004; Enck 2003; Kübler-Ross 1969, 1981; Meyers 2004; Porter et al. 2005; Quill & Byock 2000; Samarel cited in Wass & Neimeyer 1995). The work which (arguably) most influenced public perception of dying was a book entitled “On Death and Dying” written by Swiss-born American psychiatrist Elisabeth Kübler-Ross (1969). Dr Kübler-Ross personally interviewed over two hundred dying people as part of her research. From this she helped develop an “understanding of the different languages terminally ill adults and children use when they try to convey their inner knowledge” (1981, p.ix).
Dr Kübler-Ross identified five observable “stages of dying” (1) denial and isolation (“No, not me!”), (2) anger (“Why me?!”), (3) bargaining (“If I am good, then can I live?”), (4) depression (“What’s the use?”), and (5) acceptance (1969). Two of her most significant achievements are that she recognised firstly, that dying people are in fact living people who have particular feelings and needs which when acknowledged and addressed can enable them to live until death with dignity, that is, with as much acceptance and peace as possible; and secondly, that by learning from the dying we learn more about ourselves.

In this thesis, the experience of dying and facing death is not synonymous with living with a life-threatening or serious chronic illness. The emotional experience of a person who is facing imminent death is different from one who is critically ill and can intellectually anticipate death as the end of one’s existence (Chatterjee 2003-2004). Dying occurs when death is imminent and foreseeable.

While researchers, such as Dr Kübler-Ross, have observed and described what takes place during the final stages of human life, far less is known and understood about the lived and felt experience of dying. Perhaps the most important limitation faced by observers of the dying process is that the experience of dying is an inner experience. “There is no mutually common experience between the world of the living (to which researchers belong) and the world of the dying. Understanding the physical experience of the pain and suffering in the dying person requires an embodied approach, one that combines the physical, affective and social dimensions in a web of lived experiences” (Chatterjee 2003-2004, p.197).

I knew I was dying at the time I decided to undertake postgraduate research. I was later told I was dying. The cause was hypocalcaemia from widespread malignant tumours in the bone, the result of metastatic breast disease, which
was diagnosed three and a half years before. In 2004 I spent 11 days in a St Vincent’s Hospice, and on at least one occasion I was not expected to survive the week. Against all odds, I did survive. Dying was, for me, such a total and overwhelming experience. I had neither the inclination nor the ability to articulate the process at the time. Later, a RTA approach seemed the most appropriate methodology by which to recount my experiences.

Significance

The first-person account is the singularly most authoritative method of describing the lived and felt experience of dying. To date, research reveals a scarcity of first-hand accounts of the experience of dying. The significance of this thesis lies in it being written in an effort to fulfil the need for experiential accounts. This is a first-hand account, in present time, of my own experience of dying.

Aim

The aim of this thesis was primarily to describe my experience of dying. A second consideration was to describe the impact on family, friends and others.

Objectives

My initial objective was to write down my experiences in response to the many questions and concerns raised by family members and friends. I believed they were interested in making more informed decisions about their lives and treatments should they themselves be diagnosed with a life-threatening illness. Their behaviour, questions and emotional responses,
suggested that they were interested in what actually happens during the
dying process, so that they themselves could be somewhat prepared for the
eventuality. I wanted to give a true account and accurate information, which
in the first instance might help my own genetic family. Beyond this, I hoped
to reach those interested parties who would benefit from this information and
knowledge, particularly those who themselves were diagnosed with a life-
threatening illness, and those at risk of doing so. My hope was that it would
also help their partners and carers, both personal and professional, to also
know and understand the experience, so that they could give the support that
comes from knowledge and empathy.

The Researcher’s Background: My Mother, Myself

I had promised myself very early in life that I was not going to live my
mother's life. Her whole life's work seemed soul destroying; her tremendous
efforts and her self-sacrifices were unrewarded, and unrecognised. Hers was
a traditional role inherited by women of her generation and persuasion:
bearing one child after another, forever tied to house and family.

She lived in a patriarchal society, with strong Catholic beliefs and strong
family loyalties which served to inbed her in her oppressed way of life, tying
her ever more tightly to her society's culture and values - values which were
very old, going back in time as far as recorded history. She had given birth to
thirteen children. Her workload was such that she could only attend to our
very basic needs. She was servant to her husband and children. She was
constantly working; cooking, cleaning and sewing from morning till night,
day after day, year after year.
She recalled her own childhood, working the poor, yellow limestone soil with primitive tools; working beside her family in the countryside of Malta, a tiny, arid island in the Mediterranean. She would be awakened at five in the morning, given a hot, strong drink, then summoned to the fields. She would work alongside her mother, who had herself given birth to nine children. Her life too was moulded to the same ancient pattern.

My mother's schooling was not considered important. She left in fourth class, primary school. Education was thought to be wasted on girls, who were expected to marry, bear children, and toil in the old unchanging way. In Malta, there was no paid work for women. There was barely enough work for men who would often need to travel abroad to earn money. And although market gardening provided a livelihood, it was meagre, and often inadequate to sustain the family, particularly during periods of drought. Industrialisation eventually forced my mother's family to move to the city, where her father was able to find employment that provided a steady income. There, my mother became apprenticed in dressmaking, which together with lace making, was a means by which women could supplement the family income. On her own, a woman would not be able to survive on such an income, she would be dependent on her husband or family for survival. Because of this, it was essential for women to observe social norms. Women's place was well defined. Failure to comply to such norms meant social ostracism. Women were given no real choices; they conformed so that they could survive.

My mother recalled that on her wedding day she had not wanted to marry. She was married anyway. And from that day onwards, her fate mirrored that of the other village women of the island. Her predicament was sanctioned by a society for which this was the normal way of life, and it was particularly sanctioned by the priests, the virtual rulers of the land. She bought goat's milk and fresh vegetables daily from the street sellers. She washed by hand
and scrubbed on her knees. She nursed and cared for her children, and sadly lost two. She struggled alone during the years of war, with only her mother and sisters providing some comfort.

My earliest memories were of the hostel, the "silver city", our first home when we arrived in Australia. We had come by ship on a government assisted passage for migrants. We had travelled for a month to a land which provided the promise of a prosperous future for us all, the hope that our land of birth could not. This was the turning point - our lives were to be transformed. But it meant starting life among strangers - we were strangers ourselves in a foreign land.

So the family worked and survived in Australia. It seemed we grew away from the old ways of Malta. I believe we all, my sisters and I, hoped to be free of our inherited roles.

It did not occur to me till recent years that I was not in fact free, that I was living my mother's life. Outwardly, things were worlds apart - the contrast between the old ways in Malta, and the new modern lifestyle in Australia was immense. Inwardly, we women shared the same sense of hopelessness and helplessness, living lives of quiet desperation, unable to protest the injustices and indignation of being women. We depended entirely on the men in our lives: our fathers, our brothers, our husbands, our teachers, our priests and our politicians. With them was the power and the glory. Women bore the children still - and still we were dependent. Dependence meant obedience, we had no real say. No one could see, no one would hear us.

My first choice of husband now seems destined. His background was almost identical to mine, but within a year of marriage, he suffered a psychological disorder - the outcome of his own type of oppression. I became the "breadwinner" for the next four years, a predicament most unusual in the
early seventies for women of my generation. I nursed him till he grew strong, but his recovery ultimately depended on my defeat; that is, he needed the companionship of men – both as friends and as lovers. It was at this time I discovered the extent of my own oppression. I was a victim as was my mother. There was a pattern appearing that I had not noticed before.

My generation of women were the first in the family's known history to have the opportunity to support themselves and to change their circumstances. However, their choices seemed limited by an innate sense of powerlessness that had been reinforced since childhood. My older sisters married, as my parents expected, and proceeded to bring children into the world - they have now eleven between them, and all but one of their husbands has abandoned them. This one sister, who remains in an unhappy marriage, struggles with a demanding, highly successful career and also bears the sole responsibility for the upbringing of her three children. There is, finally, one remaining sister, who has shunned men altogether, preferring to relate solely to women. Even so, she too is a victim – having a history of self destructive behaviour: drugs, car accidents and abusive relationships. It seems more than a coincidence that all four of my brothers are in stable marriages.

I chose marriage and a career. Early in my marriage I tentatively considered the possibility of bearing one or two children. After deep consideration, I decided not to have children.

Earlier, in high school, I had attended an all-girls Catholic school. My performance at that school proved to be successful, and that was despite the adverse circumstances at home. I cannot doubt that my success was probably due to the absence of male peers - whose competitiveness tended to foster my sense of inadequacy. In this school I was fortunately also exposed to competent female role models.
A significant role model at the time was a woman for whom I had a great deal of respect and admiration. She was a teacher, who was head of the art school where I trained before starting work. She was strong and authoritative, a woman of considerable talent. She was not generally well liked, and she was continually being undermined by male members of staff. I liked her. Despite other people's opinions of her, I responded positively to her wisdom and instructions, and her understanding of her subject.

My training led to a career as a graphic artist and illustrator, a career which was to extend over a thirteen year period, beginning with an apprenticeship to a technical illustrator, and eventually to working in an advertising studio in the heart of London. In London, I was the only female illustrator, to three full-time and three freelance males. I was in a particularly militant mood in the two years I worked at the studio. These were the first two years directly after my separation from my first husband. My feelings of aggression, I found, were an advantage in the high powered, demanding climate of advertising. All my energy went into my work, but this behaviour was damaging to interpersonal relationships, especially alienating other women who tended towards supportive roles in the workplace. They generally made coffee for everyone, discussed personal problems, and they tended towards under-achievement. They seemed to lack confidence in their abilities, and they displayed a sense of inequality and unworthiness. I was perceived as a threat and treated with suspicion. There was a similar reaction from men. There was also an uneasiness about my refusal to discuss my private life and my disinclination to flirt. Work at that time was my life, I was single-minded about it, and that fact seemed to be a problem for everyone but me.

The problems I had while at work seemed to relate not so much to my abilities, as to the fact that I was female. For example, my application for a housing loan was turned down when I was supporting my husband; I was refused work for which I was well-qualified, because I was just married; my
wage did not generally equal a man's wage for the same work; I felt pressured to prove my loyalty to either the women or men at work; and I was often excluded from engaging in informal interactions with my peers because they were generally men. Any attempts to assert my rights would elicit a punitive reaction, ranging from being ignored, to the threat of dismissal.

Perhaps the most important issues for me regarding work were the ethics involved. These concerns eventually led to my leaving the career for which I had been trained. I was often conscious of a dilemma – artwork was an ideal choice for me, but profits were consistently valued over people. For example, my latest work involved the promotion of glamour, luxury items, cigarettes and alcohol. It became increasingly difficult to ignore the fact that my work was being used solely to make money – without any consideration being given to the consequences of promoting such items, that is, the cost in terms of human suffering.

Work, which takes into account both a sense of responsibility towards myself as well as towards others, became the major concern in my choice of work. I see a danger in working primarily for financial gain or working in an environment which fosters discrimination of any sort, whether based on the gender of a person, or that person's age, race, religion, physical or intellectual ability when these are not relevant to the job at hand. Such attitudes devalue the human element at work and they create division between people. Responsibility ought to be extended also to the natural environment on which we as a species rely.

I observe that the organisations which most influence social attitudes such as educational, political, religious and business organisations, are invariably controlled by English speaking, able bodied, Caucasian males. These are simultaneously the most powerful and advantaged positions in the country. Clearly, women and minorities are not fairly represented.
Discrimination against women ought not to be acceptable in Australia today. Such discrimination belongs to history, to the dying and dead world of my mother and her foremothers. There are signs in our modern-day Australia that employers, trade unions and governments are becoming aware of the need to demonstrate their commitment to non-discrimination; they are beginning to introduce positive procedures to promote Equal Opportunities. However, although Affirmative Action has ensured that women are represented to some extent in powerful positions, fair representation is not enforced by law; it is a "toothless tiger". When it does occur, there is some doubt as to whether women's power is actual (decision making), or token (symbolic).

Equality for women at work is not yet assured. Women are still limited in their choice of work by the fact that work relating to the private sphere tends to be unpaid, with only minimal compensation given to women with children. On the other hand, work relating to the public sphere is paid. Yet women choosing paid work are limited once again: in the type of work available to them, and in the rewards for such work. Women appear to be in a "no-win" situation. Work that women are likely to choose is not well rewarded, neither in monetary terms nor in prestige. Work that is well rewarded either in financial terms or in prestige appears to be reserved for men, particularly for English speaking, able-bodied, Caucasian men. Discrimination of this nature ensures that women do not rise to the highest positions of power.

In spite of sometimes overwhelming opposition, the women's movement has achieved much in recent years. Women's successes include: the introduction of family planning clinics, child care facilities, women's refuges, women's active participation within unions, access to work in non-traditional areas, access to higher education, and business management schemes. These
advancements improve women's prospects at work and expand women's choices.

Advances such at these are now being considered in my country of birth. Women's work, in Malta, still centres around the home, caring for a family for which they have the main responsibility. For such women, work remains unpaid and undervalued. Women in Malta, this day, have better choices.

For myself, a woman in Australia, I find there are still limitations, but at least I do have choices. I can live where and with whom I choose, and do the work I value most. To a larger extent, I can live life in the way I choose – the kind of life my mother could only dream of.

Definition of Key Terms

One of the important and formal considerations when writing this thesis was that the language I used was clearly communicated. A list of key terms and my definitions follow:

- **Alternative medicine (or therapies)**: refers to unconventional approaches to health and healing which are used instead of conventional Western medicine;

- **Biomedical or conventional Western medicine (or therapies)**: refers to the science devoted to preventing or alleviating or curing disease and injuries;

- **Complementary medicine (or therapies)**: refers to unconventional approaches to healing and health, many of which are thought to complement conventional Western medicine;

- **Death**: refers to the end of life; death of the human body is marked by the cessation of heartbeat, respiration, movement, reflexes and brain activity;
• **Dying**: refers to the imminent approach of death; losing the bodily attributes and functions necessary to sustain human life;

• **Hospice**: refers to a hospital offering terminal care facilities to help patients and their families cope with death and dying;

• **Integrative medicine (or therapies)**: or holistic therapies, refers to an approach to health and healing which combines conventional medicine with alternative and complementary medicine, an approach which accurately reflects the intrinsic link between body, mind and spirit;

• **Palliative care**: refers to the active total care of patients whose disease is not responsive to curative treatment, where the control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount;

• **Thanatology**: refers to the study or science of the experience of death and dying and of the process of bereavement.

**Thesis Chapters**

Chapter 1 described an introduction to the process of dying as foundational to the aims, objectives and significance of the research, before sharing a reflection on ‘My Mother, Myself’. The chapter also provided a list of definitions of key terms.

Chapter 2, the Literature Review, provides critiques of conventional medicine and of complementary and alternative medicine.

Chapter 3 describes the Methodology, Methods and Processes of Reflective Topical Autobiography (RTA) as reflection on the theme of dying, using autobiography as a valid approach to uncovering new knowledge.

Chapter 4 describes my experience of dying, written in autobiographical form, and addressing the aims and objectives of this thesis.
(Supervisor’s note: In Chapter 5, it was Carmen’s intention to write a Discussion and Conclusion, but her death at 5pm on Monday, 11/02/08, prevented this from happening).
CHAPTER TWO: LITERATURE REVIEW

The medical health care system and the complementary and alternative health systems have much to offer, yet these approaches to health care are limited in their responses to people with the diagnosis of widely metastasised cancer, those for whom cure is no longer the expected outcome. In this chapter are critiques of the dominant model of health care, biomedicine, and the complementary and alternative health systems, outlining their strengths and limitations.

There is no attempt in this thesis to reiterate the voluminous literature on death and dying, as this field has been reviewed intensively on many occasions, for various purposes (e.g., Bourgeois et al. 2004; Chan 2004; Enck 2003; Kübler-Ross 1969, 1981; Meyers 2004; Porter et al. 2005; Quill & Byock 2000; Samarel cited in Wass & Neimeyer 1995). The main focus of this thesis is my own experience of dying, so the literature in this chapter focuses on biomedicine, and complementary and alternative medicine, the health systems with which I came into contact.

Databases included CINAHL Plus and Medline and the search engine, Google Scholar. Key words for the biomedical section of this review used in the online searches included orthodox medicine, biomedicine, conventional Western medicine and allopathic medicine, paired in various combinations with the words death and dying. Key words for the complementary and alternative health section of this review used in the online searches included complementary medicine, and alternative medicine, paired in various combinations with the words death and dying. Many thousands of references and abstracts were derived from the search, of which the most appropriate sources were accessed and reviewed, in terms of the focus of this research.
Biomedicine

“Biomedicine” is the designation given to the professional medicine of the West; one which emphasises the fact that this is pre-eminently a biological medicine (Gaines & Davis-Floyd, 2004). As such, it can be distinguished from the professional medicines of other cultures, such as Indian Ayurveda, Japanese Kanpo and Traditional Chinese Medicine. The previously used label, “Medicine”, was problematic, in that it effectively devalued the health care systems of other cultures which were considered, by comparison, to be non-medical, ethnomedical, or merely folk – and thus thought to be inefficacious or dubious systems based on belief rather than on presumably certain medical knowledge (Good, 1994).

The term “allopathic” is often used synonymously with biomedicine, as it identifies the biomedical tradition of working “against pathology”; that is, the treatment is meant to oppose or attack the disease as directly as possible (Gaines & Davis-Floyd, 2004).

In Western culture, biomedicine inspires the hope that suffering will be alleviated and illness will be averted; that biomedical research will lead to more effective and safer drugs, provide cures for conditions, which are currently untreatable and medically incurable, and much more. At the same time, much is expected of biomedicine’s reported advances – new reproductive technologies that give hope to the infertile and allow parents to “design” their children, new stem cell treatments for spinal cord injuries and Alzheimer’s disease, new ways of screening our genomes for susceptibilities to illness, new pharmaceuticals that will not just alleviate depression but will make people happier and smarter, drugs that might further extend the life expectancy and the quality of life for those of us in the wealthy West (Rose, 2005).
Nikolas Rose, Professor of Sociology and Director of the BIOS Centre for the study of Bioscience, Biomedicine, Biotechnology and Society at the London School of Economics and Political Science, posed these questions:

How should we evaluate this complex mixture of hype and hope in relation to health? Beyond the hype, what will be the economic and political implications of these developments? Will they reshape our societies, family life, our own sense of who we are and what we can hope for? And what about geopolitics, as China, India, South Korea and many others outside the West invest heavily in genomic and biomedical research and development? Will high-tech Biomedicine exacerbate or alleviate the scandalous global inequalities in health? (Rose, 2005, p.1).

The high expectations placed in genetic and pharmaceutical solutions to disease have not been realised. The limitations of Genomic Medicine are becoming increasingly evident (Conrad & Gabe, 1999; Coulter, 2001). The so-called “O-GOD” (one gene, one disease) assumption (Conrad, 1999) has been proven erroneous. For example, the identified genes for breast cancer account for less than 10% of all breast cancer cases. This means that for more than 90% of breast cancer cases, there is no direct genetic linkage. Furthermore, the event of inheriting a defective gene does not ensure that cancer will develop. Further damage needs to occur to cause the development of cancer – from the toxic effects of unhealthy lifestyles (for example, tobacco and alcohol use, poor diet, physical inactivity); environmental carcinogens (such as exposure to chemicals, radiation), and infections (such as Hepatitis B and the human Papillomavirus) (WHO, 2006).

Except when a disease is the expression of a single gene, as in Huntington’s Disease (Conrad & Gabe, 1999), the genetic understanding of disease may prove to be extremely complex. The limitations of Pharmaceutical Biotechnology are also becoming evident. In general, the Biotech revolution
has not happened within the Pharmaceutical sector. Pharmaceutical companies are currently giving the highest priority to cancer research (see Table 1). A survey of 12 new cancer drugs, published in the British Medical Journal (2002), found that none of the drugs offered a big improvement over existing therapy, and often the costs were significantly higher – in one case 350 times higher (Moynihan, 2003).

By the “scandalous global inequalities in health” mentioned in the above quote, Professor Rose is referring to the reality that less than 10% of the world’s biomedical research funds are dedicated to addressing the problems that are responsible for 90% of the world’s burden of disease (Resnik, 2004). The world’s biggest killer is extreme poverty, coded Z59.5 in the International Classification of Diseases, and the world’s predominant burden of disease consists of the major poverty-linked diseases which are devastating poor populations, and which involve maternal and child health care, and the control of HIV/AIDS, tuberculosis and malaria (WHO, 2006). The chronic diseases, consisting of cardiovascular and metabolic diseases, cancers, injuries, and neurological and psychological disorders, are major burdens affecting both rich and poor populations alike (WHO, 2006).

The Director-General of the World Health Organisation, Dr Lee Jong-wook, provides this overview:

In the first decade of the 21st century, immense advances in human well-being co-exist with extreme deprivation. In global health we are witnessing the benefits of new medicines and technologies. But there are unprecedented reversals. Life expectancies have collapsed in some of the poorest countries to half the level of the richest – attributed to the ravages of HIV/AIDS in parts of sub-Saharan Africa and to more than a dozen “failed states”. These setbacks have been accompanied by growing fears, in rich and poor countries alike, of new infectious threats.
such as SARS and avian influenza and “hidden” behavioural conditions such as mental disorders and domestic violence (WHO, 2006, p.3).

Dr Jong-wook notes that the world community has sufficient financial resources and technologies to tackle most of these health challenges, and that what is needed is the political will.

Bioethical Considerations

In his book, “Beyond the Hippocratic Oath: A memoir on the rise of modern medical ethics” (2005), John Dossetor, Associate Professor of Medicine at the University of Colorado Health Sciences in Denver, gives a graphic account of the ethical issues involved in the practice of biomedicine. Included is his response to “ethical dilemmas” and to the highly controversial issues related to biomedicine, including biotechnology, end-of-life concerns such as euthanasia, and the “voluntary” and involuntary surgeries performed to provide an “organs for sale” market. During his discussion on research ethics, he includes the erudite and sensitive document, “Guidelines for New Therapy and Human Experimentation,” adopted by German physicians in 1931, which was subsequently ignored during the Nazi era. “It is a warning to us all,” Dr Dossetor cautions.

Dr Dossetor describes the tremendous pressures he felt to condone unethical professional behaviour during his career as a physician. Included in his book are frank admissions of both personal and systemic failures. For instance, he resigned from a paid consultancy with a medical device company when a potential ethical conflict surfaced, and he declined research training opportunities in Texas and North Carolina during a period when racism would have affected the care of people, who would be his patients or research subjects. He concludes, “The reader will find it hard to condone our passivity, and indeed, so do I.”
According to the 2004-05 National Health Survey, the use of medications is a common health-related action taken by Australians (Australian Institute of Health and Welfare, 2006). Furthermore, prescription medication alone was the most common treatment given by General Practitioners nationwide (2006, p.349). In 2004-05, there were 170 million community Pharmaceutical Benefits Scheme prescriptions – 28 million for general patients and 142 million for concessional patients. This was an increase of 2.7% over the 166 million in 2003-04 and 7.4% over the 148 million in 2000-01. In addition, there were 16 million Repatriation Pharmaceutical Benefits Scheme prescriptions in 2004-05 and 0.4 million (400,000) Pharmaceutical Benefits Scheme doctors’ bag prescriptions (that is, emergency drugs that doctors can provide patients free of charge). In financial terms, the total expenditure on all pharmaceuticals in Australia alone (including in-hospital drug purchases) in 2003-2004 was estimated at $12,576 million (AIHW, 2006).

In global terms, Pharmaceutical Biotechnology is the dominant branch of Biotech (Rose, 2005). The pharmaceutical industry is a multi-billion dollar industry. The global dollar volume is currently $825 billion (Pharmaceuticals and Healthcare Insight, 2007). Pharmaceutical companies world-wide conducted over 23,000 investigational drug programs in 2005 (BioPharm Insight™ 2006). The areas of cancer (N=5,813 or 25%), infectious diseases (N=2,474 or 11%), diseases of the central nervous system (N=2,447 or 10.7%) and cardiovascular disease (N=1,804 or 7.8%) were given priority in drug development activities, that is, over half the attention given to the combined total of all other diseases (see Table 2.1).
Table 2.1 shows the therapeutic areas for which drugs were being developed by pharmaceutical companies world-wide in 2005, and the total number of investigational drug programs that were underway for each therapeutic area (BioPharm Insight™ 2006). The pharmaceutical industry is different from most other industries, in that its products are often not chosen or paid for by consumers. Private health insurance and public health bodies (e.g. Medicare in Australia, the NHS in the UK) often pay for most of the drugs; and physicians control the choice of many drugs through prescription writing. Thus, physicians play a central role in pharmaceutical sales. Pharmaceutical companies recognise the physician’s key role, and influencing physicians in
their drug choices is a well-known marketing strategy (Myers, 2007; Robinson, 2003). Between 1995 and 2003, for example, the physician population in the US grew 15%. During the same period, the number of pharmaceutical sales reps grew 94% to more than 90,000 (Robinson, 2003).

Since 1980, pharmaceutical companies have employed new methods of marketing prescription drugs to consumers. Direct advertising is one such strategy. While direct advertising has been banned in most European countries, in 1999 the United States drug companies were allowed to advertise directly to consumers, through the US Food and Drug Administration (FDA) under the “Guidance for Industry on Consumer Directed Broadcast Advertisements”. As a result, people inquire about or even demand to receive medications they have seen advertised on television.

Another marketing strategy involves pharmaceutical companies constructing disease by pathologising normal responses and processes in healthy human beings. These practices include: the pathologising of menstruation, childbirth and menopause in women (Gaines & Davis-Floyd, 2004); the “biologised” and “culture-bound” disorders of schizophrenia and depression (Gaines & Davis-Floyd, 2004); prescribing oestrogen antagonist drugs as a so-called “preventative” strategy (or a “pre-emptive strike”) to healthy women who are cancer-free (Moynihan 2003); and the mass drugging of children for “mental health” reasons (Spillane, 2006). Such practices have been (correctly) described as crimes against humanity (Spillane, 2006, p.41).

Physicians have thus been conscripted into a systematic campaign by the pharmaceutical industry to broaden the boundaries of illness, so that drugs can be prescribed to normal and healthy people. As authors Ray Moynihan and Alan Cassels note in their book, “Selling sickness: How the world’s biggest pharmaceutical companies are turning us all into patients”, a health
system that allows drug companies to play a role in defining who is sick is fundamentally unhealthy (Moynihan & Cassels, 2005).

Other controversies and ethical concerns surrounding the pharmaceutical industry include the impact on consumers of the pharmaceutical industry’s aggressive campaign to maximise their markets. Medical writer Ray Moynihan states:

Aesculapios was the Greek god for healing and one of his children was Panacea. She is the one we all worship no matter if we’re Jewish or Christian or Muslim. We all want a panacea, particularly if we’re vulnerable or sick. The trouble is that there are vast commercial and professional forces trying to exploit the vulnerability we have, and exploit our desire for a panacea. I don’t know what is happening to the American psyche. But I see a country bombarded with advertisements. We’re seeing fear of disease, decay and death become a central part of life. I’d like people to investigate the psychic impact of being told 10 times a day you might actually be sick (Moynihan, 2005).

The Australian market is equally vulnerable to exploitation by the marketing strategies of pharmaceutical companies, however, the US is the epicentre of the “selling of sickness” or “disease mongering”. Though Americans make up less than 5 percent of the world’s population, the US makes up 50 percent of the drug market, that is, half of the total spending on drugs (Moynihan, 2005).

The role of using prescription (and other licit) drugs as a panacea is reminiscent of the role of illicit drugs in drug addiction. Prison doctor, psychiatrist and author Theodore Dalrymple, states that the temptation to take opiates and to continue to take them, arises from two main sources: first, from humanity’s eternal existential anxieties, to which there is no wholly
satisfactory solution, at least for those who are not unselfconsciously religious; and second, the particular predicament in which people find themselves (Dalrymple, 2007). Dr Dalrymple suggests that taking drugs to alleviate existential suffering is thus a displacement reaction. People who are addicted to drugs have a problem, but it is not a medical one; their problem is they do not know how to live. Dr Dalrymple concludes:

And on this subject the doctor has nothing, qua doctor, to offer. What he ought not do, however, is to mislead the addict, or allow the addict to mislead him, into thinking that the problem is medical and requires, or is susceptible to, a medical solution (2007, p.23)

Biomedical practitioners have justified their frequent use of aggressive interventions in historical terms, citing the drastic reductions in mortality that have resulted from early 20th century understandings of the aetiology of infectious diseases and the discovery of antibiotic drugs. Their critics, however, can show that disease rates were already dropping in the industrial world because of cleaner water, improvements in sewage treatment and nutrition (cited in Gaines & Davis-Floyd, 2004).

The role of pharmaceutical companies in the developing world is a matter of some debate, ranging from those arguing in favour of billions of dollars in aid provided to the developing world, to criticisms of the use of the poorest amongst us in human clinical trials, often without adequate protection, particularly in states lacking a strong rule of law (Wikipedia, 2007). Recent books and movies have been written in the west criticising the role of western pharmaceutical companies, or lack thereof, in healthcare in Africa. The most prominent of these is probably “The Constant Gardener” by John le Carre (2004, 2005), a novel that was turned into a movie. Supporters of the plot argue that it is frighteningly realistic. However, detractors including staunch critics of the industry, point out its flaws.
One example of a tragedy occurring in a developing country is described in an article published in the British Medical Journal (Kovac, 2001; Wise 2001), in which a clinical trial was conducted by a corrupt MD in Pfizer Pharmaceutical’s name in Nigeria, during a meningitis epidemic in 1996. That study allegedly used children to test the antibiotic drug ‘Trovan’, which had proven efficacious in adults, but not in children. Of 100 children tested (without informed consent) with the experimental drug “Trovan” and another 100 children tested with a gold standard drug, it was alleged that 11 children died, and others developed brain damage, partial paralysis or deafness as a result. The drug’s licence was withdrawn in Europe, because of liver toxicity and some deaths (Wise, 2001).

A related concern expressed in the last two decades by scientists, government officials, and science policy experts is the increasing role of financial interests in research. Many believe that these interests are undermining research by causing bias, error, suppression of results, and even outright fraud (Resnik, 2000). Drug companies fund an estimated 80% of medical research (Souter, 2005), and it has been found that when research is funded by drug companies, researchers are 2.6 times as likely to report positive findings (Hassed, 2006).

Former editor-in-chief of the “New England Journal of Medicine” and a member of Harvard Medical School’s Department of Social Medicine, Dr Marcia Angell (M.D.) is a recognised authority in the field of health policy and medical ethics, and an outspoken critic of the health care system. She states:

There is no question in my mind that medical researchers, educators, and clinicians have been corrupted by their close and lucrative ties to industry (Angell in Sincich, 2004).
In her award-winning book, “The truth about drug companies: How they deceive us and what to do about it” (Angell, 2004), Dr Angell states that the increase in drug spending reflects, in almost equal parts, the fact that people are taking a lot more drugs than they used to, that those drugs are more likely to be expensive new ones instead of older, cheaper ones, and that the prices of the most heavily prescribed drugs are routinely increased, sometimes several times a year. Dr Angell proposes a program of vital reforms, which include restoring impartiality to clinical research, and severing the ties between drug companies and medical education.

Biomedicine, Cancer and Australia’s Health

The general life expectancy of Australians is currently 83 years for females, and 78 years for males, placing us among the top five nations in the world (AIHW, 2006, p.xii). Almost 80% of all deaths occur in those aged 65 or over, and almost 1 in 3 (31%) occur in those 85 or over. In terms of general health, Australia ranks among the top 10 of the world’s developed countries across numerous important health indicators.

While people today are generally living longer, cancer is now the main underlying cause of death and disability in Australia, and the proportion of deaths due to “malignant neoplasms” has in fact increased (ABS, 2006). Cancer is also becoming an increasingly important factor in the global burden of disease. Over seven million people die each year from cancer, and 24.6 million people are currently living with the disease (WHO, 2007). Based on current trends, the estimated number of new cases is expected to reach 16 million annually by the year 2020 (WHO, 2007).

Malignant neoplasms were the main underlying cause for 37,989 deaths, accounting for 28.7% of all deaths in Australia in 2004. Since 1994, the proportion of deaths due to Ischaemic heart diseases has consistently
decreased from 24.1% to 18.5%, while the proportion of deaths due to malignant neoplasms has increased from 26.6% to 28.7% (The Australian Bureau of Statistics, 2006).

In 2004, the main forms of cancer causing death amongst Australian males were lung cancer (22%), prostate cancer (13%), colorectal cancer and cancer of the lymphoid and related tissues (10%) (ABS, 2006). In females, the cancers most commonly causing death in 2004 were breast cancer (16%), cancer of the trachea, bronchus and lung (15%), colorectal cancer (12%) and cancer of the lymphoid and related tissues (10%) (ABS, 2006).

In both sexes, cancer is the leading cause of death among 45 to 64 year olds, and causes more premature deaths and overall disease burden than cardiovascular disease (AIHW 2006, pp. xii & 52).

Even though prostate cancer is the most commonly registered cancer in males, the majority (65.2%) of prostate cancer deaths are among males aged 70 years and over; only 7.3% are under 60 years (ABS, 2006). For males, ischaemic heart disease, suicide, land transport accidents and lung cancer are the leading causes of potential years of life lost.

Years of potential life lost (YPLL) is a measure of premature mortality for deaths occurring between the ages of 1 year and 78 years inclusive. In 2004, the proportion of YPLL from Malignant Neoplasms was 30.4% for males, and 43.6% for females (The Australian Bureau of Statistics 2006).

For females, breast cancer is the most commonly registered cancer, and 47.3% (almost half) of all breast cancer deaths among females are under 60 years old (ABS, 2006). That is, females are dying younger from cancer compared to males (by percentage of potential years of life lost), and are four times as likely to die from cancer than from heart disease.
In global terms, breast cancer is also the most common type of cancer in women, and the most frequent cause of cancer-related deaths among women worldwide (Hortobagyi et al. 2005; WHO, 2007). In one large study, it was found that both men and women aged less than 50 years were at higher risk for advanced breast cancer (Hill et al., 2005). There is evidence to suggest that causal factors have a significant environmental component. In the Executive Summary of “State of the Evidence: What is the connection between the environment and breast cancer?” (Breast Cancer Fund & Breast Cancer Action, 2006), the authors state:

To reduce the burden of breast cancer in our society, public officials and the scientific and corporate communities must act on what is already known about agents that increase the risk of the disease. At the same time, major gaps exist in our current knowledge and we need more studies asking tough questions about the underlying causes of breast cancer. While we need further research on screening, diagnosis and treatment, decades of paying little attention to true prevention of breast cancer have resulted in needless sickness and death …

We ignore at our peril evidence that radiation and chemicals are contributing to the growing human and economic cost of breast cancer. Halting the scourge of this disease requires that we take action based on existing evidence to protect the health of people and the planet. Waiting for absolute proof brings more needless suffering and loss of lives. It is in our power to change the course we are on. It is time to act on the evidence. (2006, p.11)

These authors conclude that unless the factors that link breast cancer to environmental health hazards are clearly identified and addressed, it will not be possible to prevent the incidence and increase of breast cancer diagnoses (see also Potts 2001, 2004). The authors propose an ecological approach to
public health protection. They consider breast cancer to be not just a personal
tragedy for those affected, it is a public health crisis that requires political will
to change the status quo. These authors argue that because many of the
factors that contribute to the disease lie far beyond an individual’s personal
control, they can only be addressed by government policy and private sector
changes. They call on society, industry, the business sector and Government
bodies to support a shift of the policy agenda towards more “primary
prevention” strategies, and to adopt the “precautionary principle” to public
policy. Under this principle, indication of harm, rather than definitive proof
of harm, triggers policy action. The aim is to prevent sickness and death by
eliminating the (probable and the proven) causes.

Although “primary prevention” strategies have the potential to generate the
best results overall, Australian society continues to rely almost exclusively on
an allopathic approach to cancer, on “cancer control” strategies to manage
existing cancers, and on interventions which are applied after cancers have
developed and are detectable.

Physicians and medical scientists are becoming increasingly critical of
important aspects of the Biomedical response to cancer. Some express their
concerns publicly, in spite of the fierce backlash of intolerance and ostracism
they subsequently experience from the medical fraternity, pharmaceutical
companies and government cancer bodies. Dr John Bailar, an American
epidemiologist, who worked at the National Cancer Institute for 22 years, as
well as the Harvard and McGill universities, and who is now emeritus
professor at the University of Chicago, stated clearly in his paper titled
‘Cancer Undefeated’ (Bailar, 1997) that the ‘war against cancer’ was far from
over, and that the effects of the new treatments for cancer on mortality have
been largely disappointing. He was subsequently called a ‘murderer’ for
‘dissuading people from using the most effective cancer treatments’ (Souter,
2005, p.25). In his paper, Dr Bailar mirrored the conclusions reached by the
World Health Organisation (2007), the Breast Cancer Fund and the Breast Cancer Action (2006) groups quoted above, that the most promising approach to the control of cancer is a national commitment to prevention, with a concomitant rebalancing of the focus and funding of research (Bailar, 1997).

Leading London oncologist, Professor Michael Baum, infuriated the UK breast-screening establishment with his revised position on mammography (Souter, 2005). In the late 1980’s Professor Baum promoted its introduction. Now, in the light of further large studies and along with a number of other researchers, he raises serious questions about whether the potential benefits for a few women outweigh the downsides for the many others, particularly when it comes to screening women under the age of 50. Screening is presented as reducing a woman’s relative risk of dying from breast cancer by 30%. In real terms, 1000 women over the age of 50 have to be screened over a 10 year period in order to achieve two fewer deaths from breast cancer. Professor Baum believes the downsides of screening include: false diagnosis, over-diagnosis and over-treatment – from biopsies to unnecessary mastectomies. In a 2002 interview, Professor Baum said he resigned from Britain’s National Screening Committee:

because they were intentionally deceiving women (about the harms). They went on record saying, ‘We mustn’t let women know this because it might deter them from coming to be screened’ (Souter, 2005, p.27).

When considering surgery, Professor Michael Baum, Harvard Medical School researcher Michael Retsky and others have speculated that surgery – or even needle biopsies – on the primary tumour may have two unwanted side effects. First, by removing the tumour, surgery removes the tumour’s angiogenesis inhibitors (which slow down the rapid growth of blood cells which may help “feed” the tumour). Two, by creating an injury, it may work
as an “angiogenic switch” triggering angiogenesis in distant, dormant micrometastases (tiny clusters of cancer cells elsewhere in the body) (Souter, 2005).

German biostatistician Professor Ulrich Abel of the Heidelberg/Mannheim Tumour Centre, analysed hundreds of clinical trials and publications around the world that had looked at the value of chemotherapy for advanced, solid-tumour cancers (such as bowel, breast and lung cancers, as opposed to cancers of the bloodstream such as leukaemia). He found that there was no direct evidence that chemotherapy prolonged the survival of patients with advanced carcinoma (Souter, 2005). In the case of ovarian and lung cancer, Professor Abel found that there was some evidence of benefit, but it was small at best, and more aggressive treatments were not necessarily more effective. Nor was it clear, on the whole, that it helped with the quality of life of patients who were symptom-free. Yet, chemotherapy is a treatment routinely prescribed by oncologists (and perhaps demanded by patients) as a so-called “best practice” method.

On the benefits of chemotherapy in less advanced cancers, Professor Abel states, “In early breast cancer, the situation is rather clear. Chemotherapy can have an effect on survival” (Souter, 2005, p.27). Dr Michael Boyer, head of medical oncology at the Sydney Cancer Centre, agrees with Professor Abel’s conclusion, but cautions that to save the life of one woman with breast cancer, or to give her 5 to 10 years survival, it would mean treating 20 to 25 women who would not receive that benefit, or who did not need the treatment (Souter, 2005). Chemotherapy would have only a harmful effect on these women, because of the toxic effects of chemotherapy in addition to the symptoms of their disease.

Professor Abel also looked at the evidence for the widely held conviction that a “response” to chemotherapy – a reduction in the size of a tumour – is a good indicator of prolonged survival. He states:
Some patients don’t have a response and you can’t predict which ones will. If it’s only a partial response, that probably won’t be enough to change the prognosis. Even if some people have a complete response, what about those who don’t? They will have only the toxic effects of chemotherapy. So they will not profit – on the contrary, their survival may be shortened. So there’s an ethical problem.

The second argument is that there may be some advantage to patients with a response, but that response might also help to single out cells which resist chemotherapy and remain in the body while the others are killed (Souter, 2005, p.27).

If that were the case, he continues, the life expectancy after a relapse (a recurrence of the cancer) might in fact be shortened because these cells are more aggressive.

Associate Professor Graeme Morgan, a radiotherapist at Sydney’s Royal North Shore Hospital, supports Professor Abel’s conclusions. He argues that if chemotherapy were to disappear altogether, the 5-year survival rate of all patients with cancer would drop by only 2 percent, from 62 percent to 60 percent (Souter, 2005). His critics point out that some cancers respond well to chemotherapy, for example, the lymphatic cancers, testicular cancer and Hodgkin’s disease (Souter, 2005).

Biomedicine’s claims to success are clearly justified for some forms of cancer. Biomedicine’s effectiveness appears to be limited mainly to cancers, which have not metastasised (spread), as Professor Abel indicates in his findings. Statistics show that the (5-year) survival rate of patients with small cancers detected early (before metastasis) is substantially higher, with 83% of patients alive at 5 years, compared to 61% of those with regional spread, and only 13%
with secondary cancer, that is, those whose cancer has spread from the primary site or region, to other areas within the body (Cancer Institute NSW, 2006, p.48). These figures may appear inflated due to the “lead time bias” phenomenon, that is, because of screening and better diagnostics, some cancers are now diagnosed earlier, which means that survival time from the time of diagnosis is longer, but the point of death is the same (Black & Ling, 1990).

In summary, biomedicine’s largely allopathic approach to cancer has not resulted in a significant reduction in cancer rates. In fact, the incidence, morbidity and mortality rates of cancer continue to rise. That is, in spite of the enormous expenditure on biomedical research and practice, and the numerous Pharmaceuticals and Biomedical interventions and technologies employed in “the war against cancer”, the statistics clearly show that increasingly more people are being diagnosed with cancer, which is claiming more lives, at a younger age (see Tables 2 & 3). To reiterate, the most promising approach to the control of cancer is a national commitment to prevention, with a concomitant rebalancing of the focus and funding of research (Bailar, 1997; WHO, 2007). The government, industry and cancer bodies are called upon to act on existing knowledge and to further elucidate the causal factors of cancer, to shift to “primary prevention” strategies and to adopt the “precautionary principle” to public policy (BCF & BCA, 2006).

Complementary and Alternative Medicine

Complementary and Alternative Medicine (CAM) is defined as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (National Center for Complementary and Alternative Medicine, 2007). CAM comprises “Whole Medical Systems” theories and practices, including: Naturopathy, Homeopathy, Traditional Chinese Medicine, and Ayurveda – some which
evolved apart from, and much earlier than, Western conventional medicine (NCCAM, 2007). CAM modalities may be grouped into four main categories: mind-body medicine, biologically based practices, manipulative and body based practices, and energy medicine (see Table 2.2) (NCCAM, 2007).

Therapies within CAM are categorised as “complementary” if they are combined with conventional medicine (biomedicine) to provide a more holistic approach to health care. “Alternative” therapies are defined as those that replace conventional medicine. In different circumstances, the same CAM modality could be used either as “complementary” or as “alternative”.
**CAM SYSTEMS:**
Comprise ‘Whole Medical Systems’ theories and practices such as: Naturopathy, Homeopathy (Western); Traditional Chinese Medicine, Ayurveda (non-Western);

<table>
<thead>
<tr>
<th>Four modes of therapy:</th>
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<tbody>
<tr>
<td>1) mind-body medicine</td>
<td>e.g. patient support groups, cognitive-behavioural therapy, meditation, prayer, mental healing, creative therapies such as: art, music, dance;</td>
</tr>
<tr>
<td>2) biologically based practices</td>
<td>e.g. herbs, foods and vitamins, such as: dietary supplements, herbal products, also (unproven) cancer treatments such as shark cartilage;</td>
</tr>
<tr>
<td>3) manipulative &amp; body based practices</td>
<td>e.g. chiropractic or osteopathic manipulation, massage;</td>
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<tr>
<td>4) energy medicine</td>
<td>e.g. biofield therapies such as qi gong, reiki, therapeutic touch; &amp; bioelectromagnetic-based therapies involving pulsed fields, magnetic fields, or alternating and direct-current fields.</td>
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Table 2.2 Complementary and Alternative Medicine (CAM) Adapted from ‘What is CAM?’ by the National Center for Complementary and Alternative Medicine (NCCAM, 2007).

In Australia, “Complementary Medicines” are regulated as medicines under the Therapeutic Goods Act of 1989, and are defined as medicinal products, which contain herbs, vitamins, minerals, nutritional supplements, homeopathic medicines and certain aromatherapy products (Department of Health and Ageing, 2006). Under the Act, Complementary Medicines
comprise traditional medicines including Traditional Chinese Medicine, Indian Ayurvedic, and Australian Indigenous Medicines.

Differences exist between the CAM “whole systems” worldview and the “reductionist and materialistic” worldview of much of mainstream conventional medicine as currently practised (Bell, & Koithan, 2006). In the “whole systems” approach used by CAM, diagnoses and treatments target the person as a whole indivisible organism in his or her environmental context. In the “reductionist and materialistic” approach used by conventional medicine, diagnoses and drug treatments target the local organ or cell in isolation from, or controlled for, other environmental factors.

The CAM and conventional medicine paradigms vary also in their research methods (Bell, & Koithan, 2006). Many CAM and biomedical researchers and practitioners insist on strict scientific rigour being applied to CAM practices in order to legitimise their claims (Berman, & Chesney, 2005; Ernst, 2004; Kotsirilos, & Hassed, 2004; NCCAM, 2007). Equally, many CAM and biomedical researchers and practitioners assert that attempts to apply reductionist scientific research to CAM’s “whole systems” practices are inappropriate, and often produce conflicting and controversial results (Bell, & Koithan, 2006; Borgenson, 2005; Flesch, 2007; Hunter, & Grant, 2005; Kerridge, & McPhee, 2004a, 2004b).

Biomedical advocates assert that although randomised clinical trials may not be appropriate in assessing certain CAM modalities and products, rigorous trials are still possible (Komesaroff, 1998; Sanderson, Koczwar, & Currow, 2006). Furthermore, rigorously generated evidence assist the integration of CAM into standard medical care (Baer, 2007a; Robotin, & Penman, 2006; Cohen, Penman, Pirotta, & Da Costa, 2005). Selected CAM therapies are currently practised in the context of integrative medicine, which is the
combination of mainstream medical therapies and CAM therapies that have “high-quality scientific evidence of safety and effectiveness” (NCCAM, 2007). One important outcome is that there is a greater pluralism within health care than previously. The type of therapies available to patients within the medical healthcare system have increased, giving patients more choice and diversity in the types of treatments they receive.

The call for evidence generated by biomedicine’s ‘gold standard’ randomised clinical trials to legitimise the integration of alternative medicine into healthcare systems may be interpreted as deeply political (Barry, 2006; Broom, & Tovey, 2007). Sociological studies have illustrated clearly the strong political power of biomedicine in shaping the nature and delivery of primary healthcare (Barry, 2006; Broom, 2006; Coburn, 2006; Dew, 2000; Willis, 2006). These studies have shown that healthcare delivery was not, and is not, based solely on what is ‘safe’ and ‘effective’.

The practice of (any) medicine may not be driven by altruistic motivations alone, that is, purely by humanitarian concerns and the philanthropic care of fellow human beings. Rather, what constitutes the nature of healthcare and its delivery is a mix of physiological, contextual, ideological and political factors (Broom, 2006). The literature acknowledges that individual men and women could be altruistic and community-oriented, but also demonstrates that the medical profession as a corporate entity has often reflected more mundane interests (Friedson, 1970a &1970b). Indeed, a historical analysis of the development of biomedical dominance shows that the medical profession can and did, to various degrees and with various degrees of effectiveness, use its multiple forms of power, authority and influence to orient health care systems towards its own interests rather than necessarily the interests of its patients, the public, or the state (Coburn, 2006).
Feminist researchers assert that the ‘medicalisation and co-optation’ of CAM has serious implications for women’s health by constraining CAM’s potential to challenge, resist, and transform the hegemony and inequalities of biomedicine (Flesch, 2007). Therefore, research that speaks to the roles of women as practitioners and as students of CAM is clearly needed.

Advocates of complementary medicine also express the concern that integration within the context of biomedical dominance essentially means that the dominant status of biomedicine is not challenged. Physicians currently retain the power to exercise authority over fellow healthcare workers in matters within, and outside, their jurisdiction (Wailoo, 2004). A significant amount of research has been undertaken into professional boundary disputes and gate-keeping tactics, particularly on the part of the biomedical community (Shuval, & Mizrachi, 2004; Mizrachi, & Shuval, 2005). Focus has almost invariably been on the ways in which certain elements within the biomedical community continue to exclude, or support the sidelining of, the majority of CAMs from primary care, rather than on issues of ‘safety’ and ‘effectiveness’ (Dew, 2000; Kelner, Wellman, Boon, & Welsh, 2004).

There is, nevertheless, an increase in the demand for CAM products and treatments in the Western world (Shmueli, & Shuval, 2006; Xue, Zhang, Lin, Da Costa, & Story, 2007), an increase which occurs within the context of biomedical dominance, and which is not necessarily reflective of a significant body of scientific evidence in support of their effectiveness (Humphries, 2006). In Australia, this increase is apparent in spite of the PAN pharmaceuticals scandal concerning the manufacture of products used in CAM treatments, an event which might be expected to have undermined public confidence in them (MacLennan, Myers, & Taylor, 2006; Xue, et al., 2007).
One of the reasons cited for the significant and growing popularity of complementary medicine is people’s dissatisfaction with biomedicine and its values (Shmueli, & Shuval, 2006). A combination of factors have been discussed in the literature to determine the nature of this dissatisfaction, namely: a growing disillusionment with the technology and bureaucracy of Biomedicine and an increased questioning of its excessive invasiveness; heightened consumer awareness of the iatrogenic (detrimental physician-induced) effects of Biomedicine; and a growth in expectations for quality service (Shmueli, & Shuval, 2006).

There are complex societal factors influencing the use of complementary and alternative therapies (Broom, 2006; Willis, 2006). Other reasons given for CAM’s significant and growing popularity include: the pragmatic pursuit of better outcomes for chronic health problems (Shmueli, & Shuval, 2006), which may relate to an ‘effectiveness gap’ in medical care (Fisher, van Haselen, Hardy, Berkovitz, & McCarney, 2004); a preference for self-care (Humpel, & Jones, 2005), and ‘holistic’ or ‘natural’ approaches to health (Humphries, 2006); and beliefs about disease causation that differ from the medical paradigm (Broom, 2006).

As a form of ‘health consumerism’ CAM use has interlinked facets, which include: a market-based approach promoting individual choice (Weeks, Verhoef, & Scott, 2007); access to expert and lay knowledge through the Internet (Broom, 2006); advocacy for the inclusion of consumer perspectives within health care (Fonta, 2007), and formal mechanisms for protecting consumer rights (Department of Health and Ageing, 2006; NCCAM, 2007). The use of complementary and alternative products and therapies may thus be viewed as a social movement which advocates for greater protection of consumer interests.
In Australia, a national population-based survey was recently conducted to
determine the use and expenditure on 17 of the most popular CAM
modalities (Xue, et al., 2007). In May-June of 2005, a sample of 1,067 adults
from all Australian states and territories were recruited by random-digit
telephone dialing. The survey participants were asked about their CAM use
in the previous 12 months.

This study found that there was a higher than expected prevalence of CAM
use amongst this population. 68.9% of those interviewed had used at least
one of the 17 forms of CAM, and 44.1% visited a CAM practitioner within the
previous 12 months. The estimated number of visits to CAM practitioners by
adult Australians (69.2 million) was almost identical to the estimated number
of visits to medical practitioners (69.3 million). Almost one third (32.1%) of
these visits were to massage therapists (Western and Chinese therapeutic
massage), and more than one quarter (27.5%) were to chiropractors. The
annual ‘out of pocket’ expenditure on CAM, nationally, was estimated at 4.13
billion Australian dollars (US $3.12 billion). Less than half of the users
informed their medical practitioners about their CAM use, and their doctors
did not ask them about their CAM use. This was considered a matter of
concern because of the potential side-effects of CAM products (Webb,
Hardikar, Cranswick, & Somers, 2005) and because of possible problems
related to the contamination of CAM products (Cheung, Xue, & Leung, 2006).
It has been argued elsewhere that the rising use of CAMs does not change the
rules for informed consent (Mayes, 2004). If a physician or CAM therapist
advocates or prescribes CAMs, then it is their legal duty to warn the patient of
the material hazards, the possible complications that could occur, the
reasonable alternatives, and the effects of non-treatment (MacLennan, Myers,
& Taylor, 2006).

The most common characteristics of CAM users were: age 18-34, female,
employed, well-educated, with private health insurance coverage, and higher
than average incomes. This finding was consistent with the findings of a national survey conducted in the United States (Barnes, Powell-Griner, McFann, & Nahin, 2002). The higher prevalence of CAM use by the youngest group was largely because of their high participation rates in the practices of yoga, qigong, and t’ai chi; also because of their high use of biologically based products for reasons of clinical nutrition. Nearly half (45.8%) of all the respondents also used CAM products for reasons of clinical nutrition. The highest provider-based CAM therapies used were chiropractic, acupuncture, osteopathy, and massage therapy.

The most important finding in this study was perhaps that the prevalence of CAM use nationally (at 68.9%) was considerably higher than previously estimated (at 52.2%) (MacLennan, Myers, & Taylor, 2006). As this was a quantitative study, the reasons participants chose to use particular forms of CAM was not investigated. This was a stated limitation of this study, as was the relatively low participation rate overall.

The Australian government is currently increasing its support for complementary medicine (Baer, 2007b). The government’s main support for complementary medicine has come in the form of training programs in chiropractic, osteopathy, traditional Chinese medicine, and naturopathy in public tertiary institutions and in partnerships between private complementary colleges and public universities (Baer, 2007b). Compared to biomedical education with its requirement for hospitals and sophisticated technology, complementary training programs are inexpensive. Furthermore, complementary services are generally not covered by Medicare, but are an out of pocket expense paid for by consumers or covered by private health insurance. The government’s increased support of CAM can be thus viewed in terms of economic rationalism – as a measure to address rising health costs (Baer, 2007b).
Research shows that a significant proportion of cancer patients use CAM treatments and products, either in addition to or in combination with biomedical cancer treatments (Cassileth, & Vickers, 2005). Throughout the world, people with cancer have a relatively high mortality rate, a relatively low cure rate, and often experience multiple symptoms from cancer and its treatments (Ffnnebf, Verhoef, & Paterson, 2007). Cancer sufferers, understandably, explore all potential treatment options, including CAM modalities.

CAM and cancer research has mainly concentrated on testing a limited number of available treatments using a well-established pharmaceutical randomised controlled trial research model with tumour size and/or survival as primary outcomes (Ffnnebf, et al., 2007). CAM trials have, in general, resulted in mostly negative results when seen from the perspective of these endpoints (Ffnnebf, et al., 2007). However, cancer patients’ reasons for seeking CAM or integrative medicine were seen as not primarily related to tumour reduction and/or prolonged survival. The reasons cancer patients gave for embracing CAM were summarised as their seeking to achieve improved wellbeing whilst living with cancer (Ffnnebf, et al., 2007). This conclusion was based on the findings in the following study.

A systematic review of the literature was undertaken to determine the socio-demographics, disease characteristics, and the reasons associated with adult cancer patients’ use of complementary and alternative medicine (Verhoef, Baineaves, Boon, & Vroegindewey, 2005). Of the 500 articles found, 52 met the inclusion criteria. Most of the studies were conducted in the United States (40.4%), then Western Europe (21.3%), Canada (17.3%), the Middle East (9.6%), Asia (5.8%) and Australia/New Zealand (3.8%). Excluded from the review were qualitative studies which did not report findings in a standardised and objective manner, epidemiological reports which only discussed the prevalence of CAM use, articles in which the authors only
described oncology patients’ feelings or beliefs towards CAM, and those in which a cancer diagnosis was considered a predictor for CAM use.

The results showed that a wide range of CAM therapies was used by cancer patients, including diet and nutrition, mind-body interventions, traditional and folk remedies, pharmacological and biological treatments, manual healing methods, and herbal medicine. While many studies examined CAM use in cancer patients with all types of malignancies, those focusing on breast or prostate cancer patients were predominant. Survey designs were most common, with data being collected by self-administered questionnaires or by face-to-face interviews.

The reasons cancer patients gave for using CAM varied widely. A perceived beneficial response was stated most often (38.4%), followed by wanting control (17.3%), a strong belief in CAM (17.3%), CAM as a last resort (9.6%), and finding hope (9.6%). Some researchers have concluded from these findings that cancer patients’ reasons for seeking CAM or integrative medicine are not primarily related to tumour reduction and/or prolonged survival; and that CAM interventions are consequently often not primarily directed at affecting changes in biomedical outcomes (Ffnnebf, et al., 2007). However, it is possible to draw a different conclusion from these results. The low scores on CAM ‘as a last resort’ and of ‘finding hope’ may well be interpreted in terms of the respondents’ low expectation of the efficacy of CAM modalities. Alternatively, the low scores to these questions might indicate that CAM modalities were not seen as a last resort, but one worth pursuing; and that the respondents had not yet given up hope. This alternative explanation is supported by the fact that the respondents were predominantly people who were more educated, and were perceived as being consequently more likely to harbour cynicism towards conventional treatments (Moschen, Kemmler, & Schweigkofler, 2001; Lengacher, Benner, & Kip, 2002). The high scores given to reasons for CAM use which included ‘a
beneficial response’, ‘wanting control’, and ‘a strong belief in CAM’ may be interpreted not just as the need to improve well-being while living with cancer, but also as the need to proactively seek healing, and subsequently a positive change in biomedical outcomes.

Disappointment with conventional treatment or disappointment with a conventional practitioner were mentioned in only two studies (3.8%). The authors suggested that cancer patients who were being asked about their use of CAM in a clinical setting in which attitudes towards CAM were believed to be unfavourable, may have caused a biased response to this question (Jordan, & Delunas, 2001). The type of cancer and study design (including sample size and geographic region) did not appear to be related to the reasons for CAM use.

Women and younger individuals with cancer were found to be more likely to use CAM than were men and older individuals. This was found to be consistent with epidemiological findings which show that women tend to be higher users of health care, and are more afflicted with chronic illnesses than men (Giordano, Boatwright, Stapleton, & Huff, 2002). Also, younger patients, compared to older patients, were found to be more likely to perceive their cancer diagnosis as a threat to their future plans, and were therefore more likely to pursue health care support from CAM therapies in addition to Biomedicine (Gozum, Tezel, & Koc, 2003). This may be further evidence that cancer patients who use CAM modalities were wanting to survive, and were therefore seeking a positive change in biomedical outcomes. Higher income and more education appeared to be predictive of CAM use. This finding was expected as CAM use can be expensive, especially since it is often an out-of-pocket expense.

As mentioned earlier, patients with more education were viewed as likely to harbour more cynicism toward the conventional system and to be more aware
of CAM treatments (Moschen, et al., 2001; Lengacher, et al., 2002). A relationship between ethnicity and CAM use was not found. This finding was interpreted as a failure to detect a relationship, due to the general under-representation of ethnic minorities in the studies (Mackenzie, Taylor, Bloom, Hufford, & Johnson, 2003).

An expressed limitation of this study was that the findings could not be generalised to the wider cancer population. Language barriers excluded potentially relevant studies, and paediatric studies were excluded. Another (important) limitation was that, as the focus was on a clinic-based population, cancer sufferers who used CAM therapies and rejected or abandoned conventional medical treatment were also not included. The researchers found that the definitions and categories of CAM were not consistent but varied greatly in the literature. The authors suggested that if a standard protocol such as the NCCAM categories were used consistently in the studies, comparisons would be more valid.

Future studies were expected to focus on providing packages of care, rather than on investigating isolated CAM therapies. The authors recommended that future CAM studies of cancer patients should also focus on designing treatment decision-making frameworks. These would provide insight into the cancer patients’ decision-making process, and assist in developing appropriate educational support services such as decision aids.

As the research participants had responded to structured questionnaires containing pre-conceived categories, the authors further recommended that participants be allowed to tell their stories in an unrestrained manner, and that qualitative exploration precede quantitative studies. This recommendation for qualitative studies is well-founded. Ethnographic evidence of what is ‘effective’ in alternative medicine includes such concepts as: transcendent, transformational experiences; changed lived experience; and
the gaining of meaning (Barry, 2006). Questionnaires containing a variety of pre-conceived notions of which CAM modalities work and how they might work for cancer sufferers, do not provide the best means for accurately investigating such phenomena.

International researchers are presently exploring research strategies that are more inductive in their approach (Ffnnebf, Grimsgaard, Walach, et al., 2007). Researchers involved in several international initiatives have collected and systematically reviewed patient histories where cancer patients experienced an unexpected course in their disease process after using CAM treatments (Ffnnebf, et al., 2007). The US National Cancer Institute has concentrated on a series of what they designate as ‘best cases’, whilst the National Research Center in Complementary and Alternative Medicine in Norway have included both ‘best’ and ‘worst’ cases in their reviews (Ffnnebf, et al., 2007). The research groups involved in these initiatives envision that their efforts can better guide researchers in planning future studies.

In summary, the principal error on the part of biomedicine may be viewed as not one of focus, but one of exclusion (Zammit, 1999). The literature reviewed indicates that the biomedical community’s response to the perceived ‘challenge’ by CAM therapies may be more about retaining their dominant status rather than about ensuring public access to therapeutic treatments, which are ‘safe’ and ‘effective’. Biomedical dominance has, thus far, assured the biomedical community of continued Government funding and community support, also of having a greater say in which of the health professions and treatments are endorsed, and which are subordinated, limited, and excluded from endorsement (Long, Forsyth, Iedema, & Carroll, 2006).

It is possible to move the debate between biomedicine and CAM forward. Rather than each being ‘challenged’ by the other, such binary conceptions as
inter- or intra-professional and expert/lay relationships can evolve in relation to each other (Broom, 2006). Each may see the potential legitimacy of utilising some features of the ‘other’, and thereby reinforce or bolster their own position; for example, utilising the Internet on the part of radiation oncologists; science in the case of CAM practitioners; holism on the part of medical oncologists (Broom, 2006), and lay expert knowledge in the case of professionals (Wilson, Kendall, & Brooks, 2007).

A review of the relevant literature points to the need for a far more reflective, self-critical appraisal of the current dominant paradigm (Zammit, 1999). The increase in the use of CAM therapies might suggest that the community is proactively seeking therapeutic help of a different nature than is currently available through Biomedical practice. The community’s interest in CAM products may indicate a need for a far greater emphasis placed on self-responsibility and preventative approaches towards illness. The demand for CAM modalities might suggest the necessity to include treatment strategies in health care which are more holistic, compassionate, and humane, and which may alleviate both physical and emotional suffering. This is an expressed concern in the case of those who are diagnosed with cancer (Evans, Shaw, Sharp, Thompson, Falk, Turton, & Thompson, 2007).

CAM therapies may provide the community with safe and effective therapeutic options when (the safety and effectiveness of) Biomedical treatments are perceived to be limited; and CAM modalities may alleviate physical and emotional suffering in situations where there are no medical cures. To do this successfully, CAM professionals also need to develop skills in critical self-reflection about their own practice and about their wider profession, so as to facilitate confident and informed advocacy (Humphries, 2006). In so doing, CAM modalities have a crucial role to play in health care.
Summary

The medical health care system and the complementary and alternative health systems have much to offer, yet these approaches to health care are limited in their responses to people with the diagnosis of widely metastasised cancer, those for whom cure is no longer the expected outcome. This chapter critiqued the dominant model of health care, biomedicine, and the complementary and alternative health systems, outlining their strengths and limitations. Even though both systems have much to offer, they can still be informed by people, who are living, or who have lived, the experience of illness and cancer, and who are facing, or have faced, imminent death. The literature shows the dearth of scholarly literature on personal experiences of cancer and dying, thus this RTA is timely and important. The next chapter describes the methodology, methods and processes that guided this research project in reflecting on my experience of cancer and dying.
I chose Reflective Topical Autobiography (RTA) as the research methodology for this project, as this thesis is a self-study, a personal narrative, which reflects on a significant time in my life (Johnstone, 1999). The aim of this research was to generate new knowledge and understanding by way of examining my lived and felt experience of dying. The RTA methodology that can effectively achieve this aim is described in the first section of this chapter.

This chapter also describes the methods and processes by which I undertook the project, mindful of the theoretical assumptions of the methodology. The methods and processes section of this chapter includes ethical clearance requirements, the autobiographical methods of reflecting on my experience and the processes I used to ensure the project’s quality and effectiveness.

Reflective Topical Autobiography

Reflective Topical Autobiography (RTA) is a research methodology advanced by Megan-Jane Johnstone, who defines RTA as “an autobiographical method”, which “belongs to the genre of testimonial research and is located within the (qualitative) postpositivist, interpretive research paradigm” (Johnstone, 1999, p.24). The following is a summary of the component parts of this definition.

The word “autobiography” comes from the Greek autos (self), bio (life), and graphos (to write), and can be translated literally as “self-life-story”. An autobiography is an account of a person’s life as lived, as experienced, and as recorded or told by that person (Denzin, 1989a). When utilised as a research method, the aim of an autobiography is not to achieve “truth” in absolute terms, but to render an account of the lived experience of the self that increases our understanding of the human experience. Writing an
autobiography is itself a process of discovery, a way of knowing (Richardson, 2003). The researcher returns to the autobiography again and again to re-read, re-vision and re-tell the story in order to make changes that allow for new insights, understandings and interpretations of the meaning of the story. “Life and narrative are inextricably connected” (Ellis & Brochner, 2003, p.220). The self and story continue to evolve through ongoing lived experience.

The autobiography is “reflective” when it gives expression to a deep inner contemplation (introspection) of subjective experiences, and provides an interpretation of those experiences.

An autobiography can take one of three forms: (i) comprehensive, (ii) edited or (iii) topical (Berg, 1995; Denzin, 1989a). A comprehensive autobiography documents a person’s life story from recollections of the earliest memories to the time of writing. An edited autobiography gives a short, crisp, edited version of a person’s comprehensive life story. Of central concern to this research is the RTA, which focuses on a snap shot or a fragment of the person’s life story, that is of some topical interest (Berg, 1995). In essence, the RTA is an “excision from the life of the subject” (Denzin, 1978) and as such, “invites comparison with other (like) kinds of lives” (Berg, 1995), for the purpose of furthering our understanding of the life experiences of another (Denzin, 1989a).

The life-story that is presented ultimately is written not from an idea, but from one’s deep involvement with one’s whole state of being, in an experience or set of experiences, in particular, those involving existential moments of life discovery (Moustakas, 1973). That is, the life-story is written from the perspective of a storyteller, who has plunged deeply “into an intensive and timeless experience of the self” (Moustakas 1961, p.ix). The aim of the autobiography is achieved when “readers are able to read themselves
into, and be touched by the final report which is characteristically presented as the formal telling of the self-life-story” (Johnstone, 1999, p.25).

RTA is a methodology that makes the researcher’s own experience a topic of investigation in its own right (Ellis & Brochner, 2003). This research design gives authenticity to researchers’ direct testimony of their lived experience and to the first-person voice. By so doing, RTA is a form of testimonial research and as such, does not follow the conventions of scholarly discourse, which gives weight to abstract, categorical knowledge, and reinforces the anonymous, neutral and passive, third-person voice. Like auto-ethnography and personal narrative, the goal in this research is “to write meaningfully and evocatively about a topic that matters and that may make a difference, to include sensory and emotional experience, and to write from an ethic of care and concern” (Ellis & Brochner, 2000, p.742).

Research methodologies address the issue of how we gain knowledge about the world. Logical positivism and postpositivism are two of the multiple paradigms – or basic belief systems – used today as ways of knowing the world within the qualitative research paradigm.

The logical positivists believe in an external reality that can be understood by the methods of an objective science. Logical positivism is associated historically with the “traditional period” (1950-1970) and the quantitative research paradigm. In this period, the principles of scientific method, which were previously limited to the natural sciences (physics, biology, chemistry, and so on), were also applied to the human and social sciences. The qualitative researchers of that period attempted to justify their research methods in terms of the traditional scientific criteria of reliability and validity. Researchers sought to maintain a detached, objective stance towards the world and their objects of study. Their research methods were the (quantifiable) ways or
means by which evidence about the world was collected. The “other” who was studied was alien, foreign, and strange (Denzin, 2001).

In contrast, postpositivists assert that there may be an external reality, but it cannot be known perfectly. Postpositivists are associated historically with the postmodern or the present moment (1990-present), which is defined by the refusal to privilege any method or theory, or methods claim to validity. Postpositivism is characterised by a sensibility, which doubts all previous paradigms. The search for grand narratives – or universal truth claims – is being replaced by more local, small-scale narratives (such as autobiographies) or theories fitted to specific problems and specific situations. Qualitative research is no longer viewed from within a value-neutral or a detached, objective perspective. Class, race, gender, and ethnicity now shape the process of inquiry, making research a multicultural and a multi-perspective process. While preoccupations with the representation of the “other” remain, new theories of knowledge are emerging from these previously silenced groups to offer solutions to this problem (Denzin, 2001).

Human science research is the study of meaning (van Manen, 2001). Human science research methodologies include interpretive studies, which produce descriptions and accounts about the ways of life of the writer and those written about (Denzin, 2001). In this respect, the fundamental research orientation of all human science is more closely aligned with the critical hermeneutic (interpretive or explanatory) rationality of the humanities and philosophy, than with the more positivist (observed and analysed) rationality of the cognitive behavioural or empirical-analytic science (van Manen, 2001).

Autobiography is one of multiple forms of interpretive research methods, which also include ethnography, participant observation, and case study. The aims of interpretive research methods (which are also common to the emerging field of the sociology of emotions) are: (i) to increase our
understanding of lived experience and to make these subjective experiences more visible and intelligible, (ii) to increase our understanding of existential experiences and their meaning, and (iii) to move away from the (positivist) concept of “the detached observer”, thus paving the way for the admission of multiple realities and the multiple interpretations of lived experience (Ellis & Flaherty, 1992; James & Gabe, 1996).

The interpretive examination of lived experience implicates the totality of life, because “it relates the particular to the universal, the part to the whole, the episode to the totality” (van Manen 2001, p.36). When applied to this research, an interpretive research methodology makes possible a more holistic interpretation of events.

The RTA method relies heavily on the theoretical underpinnings of the qualitative research paradigm. A definition of qualitative research is taken from the article entitled “The Disciplines and Practice of Qualitative Research” written by authors/academics Norman Denzin and Yvonna Lincoln (2003). In their article, these authors emphasise that qualitative research operates in a complex historical field, and any definition of qualitative research must work within this field. Nevertheless, they offer the following generic definition:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.
Qualitative research involves the studied use and collection of a variety of empirical materials – case study; personal experience; introspection; life story; interview; artefacts; cultural texts and productions; observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals’ lives. Accordingly, qualitative researchers deploy a wide range of interconnected interpretive practices, hoping always to get a better understanding of the subject matter at hand. It is understood, however, that each practice makes the world visible in a different way. Hence there is frequently a commitment to using more than one interpretive practice in any study (Denzin & Lincoln 2003, pp. 4-5).

The RTA as a research methodology shares the strengths of research located within the qualitative research paradigm by including the use of “inductive” reasoning (that proceeds from a specific case or cases to a general rule) and “abductive” processes of reasoning (to the best explanation). Both are used to investigate topics not otherwise amenable to investigation by other research methods, for example, by experimental research with its emphasis on measurement and causal explanation.

The RTA also shares the theoretical assumptions underpinning the sociology of subjectivity and, more recently, the sociology of emotions. Both are largely influenced by the school of thought known as “symbolic interactionism”, which takes as its maxim: “human beings act toward things on the basis of the meanings that the things have for them” (Blummer in Ellis & Flaherty, 1992, p.2), and its counterpart “interpretive interactionism”, which speaks to the interrelationship between private lives and public responses to personal troubles, and attempts to make the private world of lived experience accessible to others (Denzin, 1989b; Ellis & Flaherty, 1992; James & Gabe, 1996).
The RTA Method

RTA adapts heuristic and phenomenological research approaches that emphasise critical self-reflection, reflexivity and total immersion in the research experience (Crotty, 1996; Moustakas, 1990; Van Manen, 2001). Johnstone suggests that the procedure for writing a RTA may involve taking the following steps (Johnstone, 1999, pp.28-29):

Choosing RTA: The researcher chooses RTA when it is an appropriate research design for investigating the (already) selected research topic.

Choosing a topic: The researcher begins with a “question” (a memorable life event) that has been “a personal challenge and puzzlement in the search to understand one’s self and the world in which one lives” (Moustakas, 1990). These events are often moments of crisis “in which individuals are so powerfully absorbed that they are left without an interpretive framework to make sense of their experience” (Ellis & Brochner, 1992, p.80). The “epiphany” or “existential moment” that emerges from the crisis is often a “turning point experience” (Denzin, 1989, p.70).

An existential moment is defined as

a moment of realization of who one is, a sudden understanding of life, an awareness of the rightness of a value or conviction or decision. It may be a moment so utterly revealing that it will alter one’s destiny, or a moment when [an] apparently enduring value is destroyed. The existential moment is sometimes the beginning of a new conviction or commitment emerging from a distinctive and particular identity. Such moments provide substance for searching, struggling, feeling, asserting, yielding, facing, and choosing a direction that challenges and enhances
realizations of potentialities both in the individual and in [that individual’s] growing relationships (Moustakas, 1973, p.2).

The researcher moves from a position of not being able to make sense of the experience, to one of being able to understand the experience, and finally to being able to give meaning to the experience.

**Immersion:** Once the topic has been chosen, the researcher plunges deeply into “an intensive and timeless experience of the self”, living this total immersion in waking, sleeping and dreaming states. The researcher continues to concentrate on the project of self-investigation. The strategies used to maintain and sustain focus include “deep and systematic introspective narrative and self-dialogue” such as those used in heuristic psychology (Ellis & Brochner, 1992; Moustakas, 1990). Through the use of these strategies, the perceptual, emotional and cognitive details of the researcher’s lived experiences can be explored, identified, and described.

**Data collection:** Once immersed in the experiences of the self, the researcher documents the key elements of the epiphany, or existential moment, that was a turning point in the researcher’s life. This involves providing a rich description of: (i) the salient event itself in which a “collision” with a conflicting idea, attitude, or world view etc. took place; (ii) the process of decision-making required as a result of this collision; (iii) the emotions associated with the decision-making process; (iv) the strategies used for coping with and adapting to the stresses associated with the epiphany or the existential moment; (v) the symbolic environment in which the epiphany or the existential moment took place; (vi) the problems experienced; and (vii) the knowledge or skills that resulted from experiencing the memorable life event. The sources of data collection include: personal journals, letters, self-dialogues (especially using the recursive questioning technique), dream analysis, essays, photographs, visual artwork (for example, drawings and paintings), and
literary works (for example, creative fiction and poetry). These may all be used to describe, explain, and give meaning to the particular life event being examined.

**Incubation:** This is a process in which the researcher “retreats from the intense, concentrated focus” of the research project to allow a deeper level of knowing and understanding to develop. The period of incubation “allows the inner workings of the tacit dimension and intuition” to continue to clarify and to develop understanding on levels outside the immediate awareness (Moustakas, 1990, p.28).

**Illumination:** occurs when the researcher experiences a breakthrough into conscious awareness of the essential and distinguishing attributes of the memorable life event, and then groups these qualities into themes. The illuminations experienced will set the parameters for writing the final RTA.

**Contemplation:** Once illumination has occurred, the researcher then fully examines “what has awakened in consciousness, in order to understand its various layers” (Moustakas 1990, p.31). This step requires deep introspection (contemplation) and reflective examination of the meanings uncovered. The researcher then selects from this contemplation the themes, the qualities of the experience, the meanings and understandings gained, the rich descriptions and representations (for example, artwork and photographs) of pertinent images that are to be used to write the RTA.

**Writing the RTA:** The way a RTA is written is not restricted to any particular discipline. However, there are three considerations or guidelines. First, is the challenge to all researchers of subjectivity to “learn how to write visually, in a way that reflects how what is seen is felt, knowing then that seeing is feeling” (Denzin, 1992, pp.24-25). Second, is the challenge to tell “mystory” in a way “that would avoid the risks of dissolving the lived experience in a solution of
impersonal concepts and abstract theoretical schemes” (Ellis & Bochner, 1992, p.98). Third, is the challenge of being willing to engage in this experiment of writing in a way that affirms the self-narrative” as a mode of inquiry that should be judged not so much against the standards and practices of science as against the practical, emotional, and aesthetic demands of life” (Ellis & Brochner 1992, p.99).

The reflective topical autobiographer takes the risk of writing expressively and creatively, using multiple modes of expression (such as poetry, photographs, paintings), and resists the orthodox expectations of academic scholarship “to write papers in prose, reference others, place our work in a lineage, objectify the topic, and focus on the expressed topic rather than on the self-as-producer” (Richardson 1992, p.125).

Data Analysis

The data of human science research are human experiences (Van Manen, 2001). We collect the data of lived experiences, because we have the potential to develop a greater understanding of our humanity. When human science research is not restricted to the description of human behaviour alone, it can be marked or motivated by concern with the alleviation of suffering. I take the view that sound scientific research shows evidence of both moral and intellectual advancement.

In this research, I used descriptive and explanatory analysis to describe the essential features and meaning of the text. A descriptive analysis was used to describe events, the sequence of events, and the contents of the artwork. An explanatory analysis was used to interpret the events, the artwork, and the research findings.
Limitations

Carey (1989) writes an articulate response to some of the challenges faced by qualitative (interpretive) studies in general:

The challenges to qualitative research are many. Qualitative researchers are called journalists or soft scientists. Their work is termed unscientific, or only exploratory, or entirely personal and full of bias. It is called criticism not theory, or it is interpreted politically as a disguised version of Marxism or Humanism.

These resistances to qualitative inquiry reflect an uneasy awareness that its traditions commit one to a critique of the positivist project. But the positivist resistance to qualitative research goes beyond the “ever-present desire to maintain a distinction between hard science and soft scholarship” (Carey, 1989, p.99).

The positive sciences (physics, economics, and psychology) are often seen as the crowning achievements of Western civilization, and in their practices it is assumed that truth can transcend opinion and personal bias (Carey, 1989, p.99).

Qualitative inquiry is seen as an assault on this tradition, leading some positivists to retreat into a “value-free” objectivist science’ model to defend their position … But these critics seldom attempt to make explicit, and critique the “moral and political commitments in their own contingent work” (Carey 1989, p.104). Denzin (2001) asserts that the opposition to positive science by the postpositivists and the poststructuralists is seen as an attack on reason and
truth. At the same time, the positive science attack on qualitative research is regarded as an attempt to legislate one version of truth over another (Denzin, 2001, pp.7884-7885).

The following is my response to what I perceive as the main concerns raised by adherents of the (positivist) scientific paradigm:

The reliability of (or the ability to replicate) the research findings: Positivist scientific inquiry ensures that knowledge can be tested over and over again and found to be accurate and consistent (Taylor, 2000). However, from the postpositive perspective taken in this research, the reliability of the findings is not an issue. This research project takes a qualitative research approach, which is based on the idea that knowledge is relative, and that it is dependent on all the features of the people, place, time, and other (contextual) factors related to the setting (Roberts & Taylor, 2002). The results of this autobiography can, nevertheless, be compared and contrasted to the findings in other studies.

A value-free, objective science: In human science research, objectivity and subjectivity are not mutually exclusive categories (van Manen, 2001). Both find their meaning and significance in the personal orientation the researcher establishes with the object of inquiry. Thus, “objectivity” means that the researcher is oriented to the object under study (Bollnow in van Manen, 2001). In human science research, “objectivity” means that the researcher remains true to the object. The researcher guards and defends the true nature of the object, remains faithful to it – aware that one is easily misled, distracted, sidetracked, or enchanted by extraneous elements. “Subjectivity” means that one needs to be as perceptive, insightful, and discerning as one can be, in order to show or disclose the object in its full richness and in its greatest depth. Subjectivity means that we are strong in our orientation to the object of study in a unique and personal way – while avoiding the danger of becoming
arbitrary, self-indulgent, or of getting captivated and carried away by our unreflected preconceptions (van Manen, 2001).

Thus, the postpositive approach taken in this research does not support the positivist scientific imperative that researchers take the role of detached observers when conducting (all) scientific research. The qualitative research approach taken in this research, questions the validity of utilising distance and objectivity to reduce bias in human science research. Rather, it “emphasises personal wisdom, lived experience, and knowledge as rich sources of material that inform writing and research” (Rosenau, 2001, p.11869). Authentic experience – like its kin “reality” and “life” – is the “ground of being in which the self is embedded” and in this research is essential to “full engagement with existence” (Lears, 2006). Consciousness itself, by definition, is:

subjective, in the sense that for a conscious state to exist it has to be experienced by some conscious subject. Consciousness in this sense has a first-person ontology in that it only exists from the point of view of a human or animal subject, an “I” who has the conscious experience (Searle, 1999).

The ability to generalise the research findings to the larger population: The methodology for this research is an autobiography. Like a case study design, which also focuses on the personal experiences and perspectives of a single individual, a RTA may be seen as limited by adherents of “the scientific method”, in that this research does not involve a representative sample of the target population (people who have lived through the experience of dying), and therefore the results cannot be generalised to the larger population.

The RTA is a research methodology that does not seek to generalise. RTA is situated within the postpositive, qualitative interpretive research paradigm,
and as such, the utilisation of “the case study of one” is not only regarded as acceptable, but as “eminently justifiable”, where the case in question “is a rare or unique event” or “serves a revelatory purpose” (Yin, 1994, p.44). Furthermore, as in the classic case study method, an individual person (or life history) can stand as “the primary unit of analysis” (Yin 1994, p.21). I support the view that the two pathways of inquiry from “experience through explanation to general theory; and from experience through expression to myth and archetype” (Reason & Hawkins, 1988, p.85) are as valid as the use of theory as the starting point of inquiry. Some of the most illuminating researchers have used both, for example, psychoanalysts Sigmund Freud (in his use of the Oedipal myth), Carl Jung (in his use of archetypes such as the Wounded Healer and the Great Mother), and scholar of mythology Joseph Campbell (in his use of myths such as the Hero’s journey) (Cherry, 1999).

Methods and Processes

This section describes methods and processes, including ethical clearance considerations, and the autobiographical methods and processes I used for reflecting on my experience and ensuring the project’s quality and effectiveness.

Ethical considerations

This project received institutional ethics approval from the HREC at Southern Cross University. Ethical issues are the concerns, dilemmas, and conflicts that arise over the proper way to conduct research (Neuman, 2003). Ethics define what is or is not legitimate research to do, or what “moral” research procedures involve. In general terms, the potential benefits of social science research – such as increasing people’s understanding of social life, improving decision-making, or helping research participants – must be weighed against any potentially harmful consequences of the research – such as a loss of
dignity, self-esteem, privacy, or democratic freedoms. Staging qualitative research as fiction frees the author from some constraints, protects the author from criminal or other charges, and may protect the identities of those studied (Richardson, 2003); however, the intention in this thesis was to give a true and accurate account of my life story. In so doing, I considered and responded to the ethical concerns that arose from undertaking this research.

The data for this PhD thesis are within my autobiography, which comprises of writing stories from my memory. Although I have written stories, the people within the stories have a right to confidentiality and anonymity. There is a risk that they may be identified. Because of this potential risk, people and places referred to in this thesis were de-identified. For example, people and places within the health care system were identified as “the doctor”, “the hospital”, etc. Family members were identified as “my sister”, or “my brother”, etc. In all cases where the participants in this autobiography may be identified, including family members, they were given the opportunity to review the stories in which they appeared, and their written permission for inclusion in this thesis was sought. Where names were necessary because of the frequency in which those people were referred to in this thesis (for example, my partner’s name) their written permission to use their first name or a pseudonym was sought.

An Information Sheet and an Informed Consent form were sent to the participants after my first draft (Appendix A). They were encouraged to edit the material; that is, to make changes related to the accuracy of the write-up, and to elaborate on information that may have been omitted or that may have needed clarification. The conditions specified in the Informed Consent form included the participants’ right to withdraw from the study at any time, without prejudice. The final draft of this thesis includes only those participants, who have voluntarily given their permission for inclusion.
As a human science researcher, I am aware that the contents of this research may have certain emotional effects on the people involved. While they may feel a level of discomfort, because my personal story and other information that might be disturbing at times, they may also experience increased awareness, insight, and feel a sense of hope and liberation. It may be possible that personal health practices and institutional health practices are challenged and, I hope, improved as a result. A list of free counselling, information and support services was attached to the Information Sheet and Informed Consent form (Appendix A).

In terms of (myself) the researcher and author, I was fully aware that others may have been concerned about my revisiting traumatic events in my life. Notwithstanding, this story needed to be told, from the point of view of the experiencing individual. I agreed to contact my mentor, Professor Beverley Taylor, or trusted friends and family members, who were available at any time if I experienced any catharsis, which I could not manage myself. Also, my private GP was aware of this research and fully endorsed it. He was available to me for consultation at any time it may have been necessary. I had unequivocal support from my husband, Michael, who is my greatest ally. He was fully supportive of this project and its processes. He was my primary support, and had knowledge of other counsellors if his support was insufficient.

The Autobiographical Methods and Processes

I applied the steps for writing a RTA suggested by Johnstone (1999, pp.28-29) in the following manner:

Choosing RTA: I chose RTA because it was an appropriate research design for investigating the selected research topic. The justification for the choice of RTA is given in the first section of this chapter.
Choosing a topic: My “question” (a memorable life event) that was “a personal challenge and puzzlement in the search to understand” myself and “the world in which I live” (Moustakas, 1990) related to my experience of dying. This event was a powerful moment of crisis needing “an interpretive framework to make sense” of my experience (Ellis & Brochner, 1992, p.80). The “epiphany” or “existential moment” that emerged from the crisis was the “turning point experience” (Denzin, 1989, p.70) that my experience may be of benefit to other people facing death.

My existential moment at the point of realising the certainty of imminent death gave me “a sudden understanding of life”, and a “new conviction or commitment” to write my life story of dying. This decision led to this RTA, in which I experienced moments of “searching, struggling, feeling, asserting, yielding, facing, and choosing a direction that challenges and enhances realizations of potentialities” both in myself and in my “growing relationships” (Moustakas, 1973, p.2).

Through writing the RTA, by making reflective journal notes, undertaking the art work and reflecting on their meaning, I moved from a position of not being able to make sense of the enormity of the dying experience, to one of being able to understand the experience, and finally to being able to give meaning to the experience.

Immersion: Once the topic had been chosen, I plunged deeply into “an intensive and timeless experience of the self”, living this total immersion in waking, sleeping and dreaming states. I continued to concentrate on the project of self-investigation, resting when I needed a break from the writing, reflecting and imaging. My concentration was assisted by phone calls and emails to the University, rather than attending in person each fortnight. This
directed my energy towards the RTA itself, rather than travelling a one-hour round road trip.

I maintained regular contact with my PhD Supervisor and relied heavily on my own sense of wellbeing and of keeping my interpersonal boundaries, to sustain my reflective efforts over time. I had an unspoken agreement with my Supervisor to make progress as quickly as possible, but I was careful not to overload myself at any time with social and intellectual activities. For example, if I experienced negative emotions in any of the writing, such as in reading and critiquing the biomedical model literature, I paced myself so that the task did not deplete my energy unnecessarily. At times, I moved between the tasks of academic writing, reflecting and making images, so that I could enjoy the process as much as possible without undue stress. Through these strategies, I explored, identified, and described my lived experiences of dying.

Data collection: Once immersed in my experiences, I documented the key elements of my existential moments of awareness in the dying process, including: conflicting ideas, attitudes, or world views; the process of decision-making required; the emotions associated with the decision-making process; the strategies I used for coping with and adapting to the stresses associated with the process of dying; features of the symbolic environment; the problems experienced; and the knowledge or skills that resulted from experiencing the life event of knowing I was dying. The sources of data collection included: a personal journal, self-dialogues, discussions with family and friends, my own dream analysis, and visual artwork, such as drawings and paintings. I also used literary works, such as music and poetry, in public and professional presentations of my research project (Zammit, 2007a,b; see also Appendices B and C). These assisted me to describe, explain, and give meaning to the particular life event I examined.
Incubation: From time to time, I retreated “from the intense, concentrated focus” of the research project to allow myself a deeper level of knowing and understanding. I practised meditation regularly and enjoyed continued participation in my personal interest groups, thus giving me a period of incubation to allow “the inner workings of the tacit dimension and intuition” to continue to clarify and to develop understanding on levels outside the immediate awareness (Moustakas, 1990, p.28).

Illumination: I experienced illumination when I was undertaking the research activities, such as writing, reading and in doing the art work. I experienced a breakthrough into conscious awareness of the essential and distinguishing attributes of my own dying processes, and these have been recorded in this document in Chapter Four. The illuminations experienced set the parameters for writing the final RTA.

Contemplation: Once illumination occurred, I examined fully that which “awakened in consciousness, in order to understand its various layers” (Moustakas 1990, p.31). This step required deep introspection (contemplation) and reflective examination of the meanings uncovered. I then selected from this contemplation the images and reflections that speak of the qualities of the experience and the meanings and understandings I gained.

Writing the RTA: In writing the RTA I began from the standpoint of understanding and applying the challenges of subjectivity, so that I could write in the deepest and most revealing way, thereby writing visually, in a way that reflected how “what is seen is felt, knowing then that seeing is feeling” (Denzin, 1992, pp.24-25). This meant that I when I was working actively on writing I plunged my reflections to the deepest parts of my memories, being as honest with myself as I could possibly be, in order to recapture the essential aspects and messages of my memories. As this was a deeply intense experience requiring considerable cognitive engagement, I
rested when necessary, or played music, meditated, or simply took time out on the back patio with my partner, looking at the rainforest and birds in our backyard.

I was mindful of the challenge to tell “mystory” in a way “that would avoid the risks of dissolving the lived experience in a solution of impersonal concepts and abstract theoretical schemes” (Ellis & Bochner, 1992, p.98). I did this by reminding myself of the aim and objectives of the project, so that these intentions could be fulfilled most faithfully. I faced the challenge of being willing to engage in this experiment of writing by making it “mystory”, by owning my actions and emotions and always trying to affirm my self-narrative as writing that could be “judged against the practical, emotional, and aesthetic demands of life” (Ellis & Brochner 1992, p.99). As I wrote the RTA, the meaning of my experience became illuminated progressively, and I was aware increasingly of the importance of the practical, emotional, and aesthetic aspects of my life.

As mentioned previously, I was willing to take the risk of writing expressively and creatively, using multiple modes of expression, such as poetry, reflections and paintings. I developed my artistic ability when I worked as a graphic artist and illustrator early in my working career. It was a kind of apprenticeship – I would learn skills at the studios that interested me, such as fashion illustration, photo-restoration, and airbrush art. When I became proficient in these areas, I would then move to work elsewhere to develop other techniques and thus continue to refine my skills. My career culminated in my eventually working as a storyboard illustrator at an art studio in the heart of London. My artistic career came to an abrupt end after this when I could no longer ignore the soulless nature of working in advertising. I decided to change directions. I wanted to go to University to undertake a Bachelor of Arts degree in Behavioural Studies, a psychology-based course. I have since then also attained a Masters degree in Art Therapy,
a course of study that enabled me to create art as an expression of my inner life. Since undertaking my University studies, I have worked as a counsellor mainly in the areas of drug-addiction, domestic violence and family therapy.

When I became very ill and unable to work professionally, friends and family suggested that I return to artwork as a hobby. I believe they were suggesting that I produce “pretty” pictures of flowers, landscapes and such, representative artwork that comes from the “outside-in”. Except perhaps for portraiture, this type of artwork has never interested me greatly. Since I gave away producing artwork for advertising purposes those many years ago, I became increasingly interested in looking beneath the surface of things, beneath the superficialities; also in producing work that was beneficial to our community. I subsequently became determined to only produce words and pictures that were meaningful, that communicated something of importance. The methodology I chose for this doctoral thesis has given me the opportunity to express myself in this way, to finally produce words and art that came from the “inside-out”.

In the artwork I created for my thesis, I wanted primarily to convey the emotional journey. This was because I discovered that how I was feeling emotionally during my illness and treatments did not generally concern those to whom I turned for assistance. Yet, my emotional state was as real to me as my physical state. Furthermore, I believe that one of the major causes of my illness was the fact that I had ignored my emotional reality. I had focused on “doing” and “achieving”, in spite of how I was feeling. For example, I ignored how stressed I was feeling when I was working in very difficult areas of counselling, and studying at the same time.

It was also important to me when I rendered my drawings for this thesis that I actually captured the emotion that I wanted to convey. I decided to test the effect of each drawing on family and friends. For example, when I created the
two drawings entitled “Morphine” and “Withdrawal/Emergence”, I made a point of not showing them to my partner until they were finished. Then I watched his reaction. Michael’s response was quite emotional and he responded in a different way to each of the drawings, affirming to me that I was successful in achieving the emotional tone that I had wanted to communicate.

Even though I had academic qualifications, I resisted the orthodox expectations of academic scholarship “to write papers in prose, reference others” and place my work in a lineage, which might “objectify the topic”. Rather, even though it was the most personal and urgent life topic that I could possibly relate, I nevertheless focused on the experience of dying, rather than on (my)”self-as-producer” (Richardson 1992, p.125).

Criteria for Ensuring the Quality and Effectiveness of the Project

In terms of analysing this research project for its quality and effectiveness, I was guided by the criteria established by Dr Laurel Richardson: Professor Emerita of Sociology, Professor of Cultural Studies in the College of Education, and Graduate Professor of Women’s Studies at the Ohio State University (in Denzin & Lincoln, 2003). She has written extensively on qualitative research methods, ethics, and issues of representation. The following is Dr Richardson’s criteria for evaluating creative analytic practices (“CAP” ethnographies, including auto-ethnography and personal narrative):

1. **Substantive contribution:** Does this piece contribute to our understanding of social life? Does the writer demonstrate a deeply grounded (if embedded) social scientific perspective? How has this perspective informed the construction of the text?

2. **Aesthetic merit:** Rather than reducing standards, CAP ethnographies add standard. Does this piece succeed aesthetically? Does the use
of creative analytic practices open up the text, invite interpretive response? Is the text artistically shaped, satisfying, complex, and not boring?

3. **Reflexivity:** Is the author cognizant of the epistemology of postmodernism? How did the author come to write this text? How was the information gathered? Are there ethical issues? How has the author’s subjectivity been both a producer and a product of this text? Is there adequate self-awareness and self-exposure for the reader to make judgements about the point of view? Does the author hold him or herself accountable to the standards of knowing and telling of the people s/he has studied?

4. **Impact:** Does this affect me? Emotionally? Intellectually? Does it generate new questions? Move me to write? Move me to try new research practices? Move me to action?

5. **Expression of reality:** Does this text embody a fleshed out, embodied sense of lived experience? Does it seem “true” – a credible account of a cultural, social, individual, or communal sense of the “real”? (Richardson, 2003, pp. 522-523)

Richardson notes that research practices are essentially concerned with enlarged understanding. Science offers some research practices; and literature, the creative arts, memory work, and introspection offer still others. She suggests that science is one lens through which to look and see, creative arts is another: “We see more deeply using two lenses. I wanted to look through both lenses, to see a ‘social science art form’” (Richardson 2003, p.523). In this sense, science and the creative arts are no longer considered to be mutually exclusive and incompatible. They are seen as mutually enriching: one form of knowledge and practice informs the other.

From my point of view, it is clear that images and symbols communicate in a different way to the spoken and written word. They speak to our
unconscious needs and desires and in this way are powerful forces, much used today to shape human behaviour. The integration of the creative arts with science offers a way towards ensuring that the images and myths we create are (more) accurately interpreted and their meanings (more) clearly understood.

The extent to which I have achieved the criteria for the quality and effectiveness of the project, probably lies with the reader, rather than with me, as the author of this text. This fits with the postmodern idea that we are all interpreters of life texts, and our own “reading” is of value (Rosenau, 2001).

During 2007 I presented the project to various audiences (Zammit 2007ab). After the first presentation (Zammit 2007a, Appendix B) I realised that the work had such a profound effect on people, that I needed to allow time at the end of the presentation for debriefing of the audience, so they had time to express their emotional responses to the artwork and reflections (Zammit 2007b, Appendix C). In each presentation, the audiences were silent throughout the session and at times I noticed tears in people’s eyes as they listened to my story, and possibly revisited their grief from their experiences of loss, dying and death of people and relationships. Although I did not evaluate the responses in an objective way to ascertain the audiences’ answers to the specific quality and effectiveness questions (Richardson, 2003), I could infer that my life story resonated with many people, some of whom came up to me later to tell me of the impact my artwork and reflection had on them personally.

**Summary**

In this chapter I described RTA as the research methodology for this project, as a self-study, personal narrative, which reflected on a significant time in my
life (Johnstone, 1999). The aim of this research was appropriate for a RTA approach, because it had the potential to generate new knowledge and understanding by way of examining my lived and felt experience of dying.

This chapter also described the methods and processes by which I undertook the project, including ethical clearance considerations, the autobiographical methods of reflecting on my experience, and the processes I used to ensure the project’s quality and effectiveness. Ethical considerations recognised the confidentiality and anonymity of “characters” within my stories and I made every attempt to protect these rights, by the careful application of processes described within this chapter. The autobiographical methods and processes of reflecting on my experience of dying were congruent with Johnstone’s (1999) steps of writing a RTA and the epistemological assumptions of qualitative research described in this chapter. I used Richardson’s (2003) questions to assess the quality and effectiveness of the RTA. My informal process of listening to responses from audiences at my project presentations leads me to assume that my artwork and reflections were judged at high levels of appreciation, in relation to my RTA’s substantive contribution, aesthetic merit, reflexivity, impact and expression of reality.
CHAPTER FOUR: MY REFLECTIVE TOPICAL AUTOBIOGRAPHY

Introduction

When I began to write my RTA, I realised that my experiences had a trajectory of events, which needed to be documented chronologically, to capture the detail of my life journey, in relation to my cancer diagnosis. This chapter provides a sequence of events and my reflections on these events. Being an artist, I decided to use artworks to portray my experiences, so this chapter also presents my artworks and my reflections on creating and interpreting these images.

The Sequence of Events

Table 4.1 outlines my encounter with biomedicine, from the time I first perceived the lump under my arm in October 2001 until September 2005. In this section I discuss the events shown in the Table. I also analyse the strengths and limitations of the biomedical model, as I perceived them, during this time.

At first glance, when looking at Table 4.1, this seems to be a comprehensive summary of the significant events over a four-year period. As I take a closer look at the sequence of events, I notice that a critical omission has been made, in order to be concise. A fuller description of my emotional experience is missing. How I felt at the time – at each point along the timeline – is, in fact, as significant to me as the event itself. Perhaps the most important reason that I feel a need to express and include my emotional response to these events is because I believe, in retrospect, that my previous (learned) inclination to dismiss my emotional experience was a significant causal factor in my developing cancer.
### Table 4.1 Timeline of Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Treatment</th>
<th>Result</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct. 2001</td>
<td>Discover underarm lump</td>
<td>Fine needle biopsy (doctor)</td>
<td>“Fibro adenoma”</td>
<td>Lump remains untreated</td>
</tr>
<tr>
<td>Feb. 2002</td>
<td>Lump seems to change</td>
<td>Core needle biopsy (specialist)</td>
<td>Positive for cancer</td>
<td>Lump grows at alarming rate, terror</td>
</tr>
<tr>
<td>Feb. 2002</td>
<td>Referral to surgeon</td>
<td>50mm tumour + 16 nodes excised</td>
<td>(Metastatic) invasive ductal carcinoma</td>
<td>Pain, drain, swelling, distress, shock</td>
</tr>
<tr>
<td>Apr. 2002</td>
<td>Referral to oncologist/s + tests</td>
<td>Surgery+ radio+chemo+hormonetherapy urged</td>
<td>Hormonetherapy (Tamoxifen+Zoladex)*</td>
<td>Menopause, hot flushes, fatigue</td>
</tr>
<tr>
<td>Apr. 2002</td>
<td>Complementary therapy (doctor)</td>
<td>Vitamins, Iscador*, diet, group work, meditation</td>
<td>Body/mind/spiritual nourishment</td>
<td>Clearer, calmer</td>
</tr>
<tr>
<td>Aug. 2002</td>
<td>Need change of lifestyle</td>
<td>Leave Perth for Sydney to live near family</td>
<td>Co-manage retreat centre</td>
<td>Additional stress, ends in crisis</td>
</tr>
<tr>
<td>Feb. 2003</td>
<td>Need change of lifestyle</td>
<td>Leave Sydney for the Northern Rivers of NSW</td>
<td>Find a new (peaceful) home</td>
<td>Settle down again</td>
</tr>
<tr>
<td>Mar. 2004</td>
<td>Fall over in bedroom</td>
<td>Physiotherapy for sprained back</td>
<td>Not effective</td>
<td>Pain, stiffness, cough develops</td>
</tr>
<tr>
<td>Mar. 2004</td>
<td>Excruciating pain, rigidity, tremor</td>
<td>Bone scan, kidney function test (for yellow skin)</td>
<td>Bone tumours, v. high calcium in blood</td>
<td>Death imminent, Zometa* given</td>
</tr>
<tr>
<td>Apr. 2004</td>
<td>Referral to radiation oncologist</td>
<td>Tattoos only ~ too sick for radiation treatment</td>
<td>Stay overnight (Brisbane), deteriorate</td>
<td>Referred to Emergency</td>
</tr>
<tr>
<td>Apr. 2004</td>
<td>Severe pain</td>
<td>Private Hospital refuses treatment</td>
<td>Ambulance to Public Hospital</td>
<td>Admitted to Resuscitation Room</td>
</tr>
<tr>
<td>Apr. 2004</td>
<td>Bone cancer, pneumonia</td>
<td>60mg morphine + antibiotics in drip</td>
<td>Pain control, pneumonia heals</td>
<td>Oncologist consulted again</td>
</tr>
<tr>
<td>Apr. 2004</td>
<td>Referral to Hospice</td>
<td>180-200mgs morphine daily + other drugs</td>
<td>More comfortable, feel safe</td>
<td>Crisis passes, depression, constipation</td>
</tr>
<tr>
<td>Apr. 2004</td>
<td>Ask to go home</td>
<td>Return home</td>
<td>Less alone, less anxious</td>
<td>Pain, hallucinations, panic attacks, suicidal</td>
</tr>
<tr>
<td>May 2004</td>
<td>Referral to radiation oncologist</td>
<td>One-off intensive radiation treatment (Brisbane)</td>
<td>Treatment works = less pain</td>
<td>Seek relief from other symptoms</td>
</tr>
<tr>
<td>Jun. 2004</td>
<td>Consult community nurse&amp;doctor</td>
<td>Celepram* chosen (anti-depressant)</td>
<td>Treatment works within 3 days</td>
<td>Relief from panic attacks &amp; depression</td>
</tr>
<tr>
<td>Jun. 2004</td>
<td>Condition stabilises</td>
<td>Morphine + other drugs continued</td>
<td>Begin to sit, stand and walk without aid</td>
<td>Develop confidence, optimism</td>
</tr>
<tr>
<td>July 2004</td>
<td>Become independent</td>
<td>Reduce morphine + other drugs</td>
<td>Withdrawal symptoms</td>
<td>Pain, restlessness, sleep disturbance,</td>
</tr>
<tr>
<td>Oct. 2004</td>
<td>Continue withdrawing</td>
<td>Reduce morphine + other drugs</td>
<td>Withdrawal symptoms</td>
<td>Day &amp; night sweats, nausea, fatigue</td>
</tr>
<tr>
<td>Aug. 2005</td>
<td>Continue withdrawing</td>
<td>Reduce morphine + other drugs</td>
<td>Withdrawal symptoms</td>
<td>Reach goal = no morphine</td>
</tr>
</tbody>
</table>

* Iscador is an extract in water from the mistletoe plant, which is injected subcutaneously. Iscador was developed in Switzerland and Germany in the 1920’s by doctors working with philosopher Rudolph Steiner, from an understanding called anthroposophy which means “study of the wisdom of man”.

* Zometa is zoledronic acid injected intravenously for tumour-induced hypercalcaemia, given in a saline drip initially every three weeks then every four weeks.
* Celepram is citalopram hydrobromide, a selective serotonin reuptake inhibitor (SSRI), one tablet taken daily (orally) to medically treat depression.
* Tamoxifen is an antagonist for oestrogen, which is used in the treatment of breast cancer, taken daily (orally) in tablet form.
* Zoladex is goserelin, a drug used to treat early and secondary breast cancer in pre-menopausal women, who have oestrogen receptor positive tumours (breast cancers that are sensitive to oestrogen). It is a synthetic version of a natural hormone that controls how the ovaries work. Zoladex is an implant, a pellet that is injected subcutaneously in the abdomen on a monthly basis.
Perth, Western Australia

The Lump

On a Sunday in late October 2001, I attended a women’s self-care workshop at a country retreat. My work as a professional counsellor in the area of domestic violence and marriage counselling was stressful, and I had looked forward to this much needed form of self-nurturing. I chose to have a trigger point massage to begin the day. Looking back now it is interesting to me that I was asked to sign a waiver. This had never been required of me before, and as I’d never had problems with receiving massages, I agreed to sign. After the massage, which was actually more painful than relaxing, I attended a belly dance class.

While I practised the sensuous movements with my arms held above my head, I felt a sharp pain that shot up from my outer left breast to under my arm. I was wearing a tight bra that day and I believed that it might have caused this discomfort. Nevertheless, it was a strange and scary feeling. I didn’t dare examine myself at the time, so I left it till later in the evening when I was at home. My worst fears were realised, as there was a lump under my arm.

I saw my doctor as soon as possible. She said to have the lump taken out straight away. I now believe that this was the right advice. Had I known what the implications were of making the wrong decision about this, I would not have thought twice, I would definitely not have hesitated to have the surgery. I would also have been much more amenable to the idea had she talked about seeing a “specialist” instead of a “surgeon”. At that time, I did not understand the reason she made this recommendation, and I was not convinced by the reasons she gave. I opted for the second alternative, that is, to have a fine needle biopsy, which was, I was told, to check whether it was malignant or benign. I was later to deeply regret this decision. I remember asking whether
it would cause spread of the disease if it should be malignant. I was assured it would not. So, I proceeded with the biopsy, quite shocked and concerned at the number of times the lump was pricked. When the results returned, it showed a negative result, the lump was considered to be benign. I asked the doctor whether the lump was in my lymph nodes. She replied that the pathology test results suggested that it was not.

After several weeks, I noticed a change in the size and hardness of the lump. The doctor said that the change was imperceptible to her. This was the second time I felt that my concerns were not taken seriously. One previous time was when I went to the surgery, because I felt a “pins and needles” sensation in my left hand and up and down my left arm. This was some months before I discovered the lump. I now believe that the “pins and needles” sensations I felt were the first indication that something was wrong in that arm. The doctor again said that the indications suggested that the lump was benign. I asked her for the name of the surgeon she recommended. I said that I would be willing to see him for a check-up and discussion.

I did not act on this straight away, as I was beginning to wonder if I was, in fact, taking this too seriously, but the nagging feeling of the changes in the lump eventually led me to see the surgeon. This was now February, about four months after I first became aware of it. The surgeon gave me a thorough manual examination, pressing the lump and the general underarm area. He said that, in his professional opinion, the lump was in my lymph nodes and there was more than one. He said he believed that the results I was given were wrong and he recommended strongly that I have the test again at the labs at the hospital where he worked. He asked me if I wanted to contact the original doctor to let her know the outcome of this interview. I asked him if he would please make the call, and to make sure that he tells her that not only were the test results possibly wrong, but that the lymph nodes were probably involved. I followed his advice to have a core biopsy and ultrasound. He then gave me
the shocking and terrible news that the three lumps they found were malignant, and in the lymph nodes.

*Surgery*

The surgeon I first consulted was in private practice, and as I was not privately insured, I asked him to refer me to a surgeon, a breast specialist, who practised in a public hospital. The public hospital set-up was actually quite good. There were two nurses there, specifically to support patients through their initial through to their final interviews. During my first appointment, a nurse sat with me, held my hand, and described what would take place in my interview with the surgeon, answering any questions I had. She also sat in on my two interviews with the surgeon and afterwards. The surgeon was regarded highly in her field, especially by the nurses, which I believed was high recommendation indeed. Student doctors, who took an interest in my case, accompanied the surgeon. She looked over the notes, again examined my underarm, and asked for permission for the students to also feel the lump. She described the lump as “angry”. She recommended further tests and concluded: “Yes, we’ll whip it out.” The earliest date for surgery was 19th February 2002, the following week.

Amongst a lot of pertinent questions, Michael, my husband, asked the surgeon about lymphoedema. He had been a nurse for 10 years, earlier in his career. I, as a layperson, would not have known to ask that question, and I certainly did not know how important the implications were. Her recommendations on most things were based on statistical results. For example, she said that statistics showed that there was less than 10 percent chance of developing lymphoedema – the swelling of a limb after the removal of the associated lymph glands; this is permanent painful condition, which can be managed to some degree. I later discovered that this figure was a gross underestimation of the true risk – because whatever the figure given, it was conditional upon a
number of considerations - how many nodes were involved, whether or not radiotherapy was given, and on the time frame, that is, did those statistics apply straight after the surgery, or after radiotherapy? For how long would the risk remain less than 10 percent; for a year, or five, forever?

I was later to discover this was a lifetime risk, no less, and a possibility that had to be managed on a daily basis, so that it might be prevented. No matter how well a person performed preventative measures, there were no guarantees. In fact, I have found that of the people I knew, who had undergone radiotherapy as well as surgery, all had developed lymphoedema, sometimes straight after treatment, sometimes three or four years later. In one case I know, for example, fifteen nodes were removed, none were affected, and she had radiotherapy to the nodes and developed lymphoedema three and a half years later. This fact on its own is, of course, not the most important consideration and ought not be a deterrent, but it is a strong argument for electing to have a sentinel node biopsy before surgery, so that only the affected lymph nodes are removed. The fewer the nodes removed, the less chance of developing lymphoedema. In my case, sixteen nodes were surgically removed, and only five were affected.

From the time of the second biopsy the lump was growing at an alarming rate. During this waiting period I attended the appointments for the recommended tests. I was not prepared for the harshness of the procedures, nor for the anxiety they produced. After a MRI breast scan, for example, I phoned Michael in great distress, as I felt on the verge of collapse, and I was not sure how I was going to make it home. Michael was not always able to accompany me to the number of tests and interviews I had, as he was now the breadwinner and my only financial support. By the time of the operation, the mass under my arm was feeling large and painful. My operation was scheduled first on the list that day, however, there were unexpected delays. As it turned out, I was in the pre-op section most of the day. It was not clear to me why I was delayed, though I kept asking through a haze of sedatives. I was finally told that the doctor was
waiting for a particular test result before proceeding. The nurse said they might, in fact, not proceed. I could hardly believe this, as the lump was now intolerable. I also remember the woman in the next bed being asked if she wanted a sentinel node biopsy, to which she agreed. I wondered why I was not given a choice. I was finally wheeled into the operation theatre towards the end of the day.

In the post-op interview with the surgeon I was given the pathology results of the tumour and a referral to an oncologist who would recommend further treatment. The pathology results showed that the exact nature of the tumour. Both Michael and I were devastated.

Oncology

The oncologist ordered more intensive scans, before proceeding with recommendations. One of them was a bone scan, which would indicate whether the cancer had yet metastasised (spread) to the bone. This is when I discovered the reason for the delay in my operation. The surgeon had initially treated the lump as the primary (source of cancer), but one of the earlier test results showed that it was a secondary. In other words, the cancer had already spread. The bone scan was clear, but now I began to understand why the treatments that the oncologist was talking about were more intensive than the surgeon had indicated.

Then came the list of horror treatments she recommended: more surgery, chemotherapy for six months, radiotherapy for six weeks, and hormone treatment indefinitely. I sought the opinions of four other oncologists. All gave the same list, except for one, who also wanted to throw in a mastectomy, maybe two, just in case. So, I went back to my original oncologist. She examined the lymph nodes in my throat, and suggested I have the lymph nodes on both sides excised. One scan showed a lump in my thorax, so she
recommended surgery to remove it as well. I refused a biopsy. She recommended strongly that all the treatments she listed to be done as soon as possible, all, and she was no longer talking about a possible cure. I asked her why the hormone therapy was not given in the first, rather in the last instance, since the tumour appeared hormone dependent. She repeated the list, and the order that the treatments should be given. I asked her in the first instance, if she could arrange for me to talk to three people who had undergone this treatment so that I could make a more informed decision. She declined. I asked her, then, to begin with the hormone treatment and to monitor the results. If the tumour grew or there was no change, I would reconsider her recommendations. She agreed to this and prescribed daily Tamoxifen another drug, which was a pellet, that was inserted into my abdomen monthly, starting straight away.

During the time I had to decide about treatment, I was so stressed and still in shock, that I found it extremely difficult to think clearly and to make the crucial decisions necessary, decisions that would either save me (for a time) or precipitate my death. One doctor I consulted, a general practitioner, was very interested in helping cancer patients with nutritional and lifestyle advice. She ran retreats, gave Vitamin C injections and prescribed Iscador to interested patients. I sought her advice when I felt pressured to make an important decision. I was distraught. She asked me what I wanted to do. I said that I wanted to go on a seven day Buddhist meditation retreat to clear my mind. She supported me wholeheartedly, saying that she also believed it was not a good idea to make such important decisions while I felt so distressed. While I was on retreat I imagined the tumour shrinking away to nothing. We checked the results in a month and a half and the tumour in my thorax was no longer there.
Northern Rivers, New South Wales
February and March 2004, two years after initial medical diagnosis.

The Fall

One morning as I was in the bedroom, I tripped over a part of the bedspread that was lying on the floor. I landed fully on the floor, on my back and side. The fall resulted in pain and stiffness that did not subside over time, so I consulted my doctor for a sprained back. He recommended a physiotherapist to begin with, to check my symptoms and to give me remedial exercises. At about the same time I also developed a cough, and every time I coughed my back would collapse a little. This went on for some weeks until one day, as I was returning from a neighbour’s place, and after having a coughing fit, my back collapsed to the point that I needed Michael’s assistance to walk home. As the afternoon progressed, the level of pain increased and I became less able to walk. By night-time, I was barely able to move, but I was comfortable enough to sleep. During the night, not wanting to wake Michael, I got up to go to the toilet alone, but once I managed to pull myself into an upright position, I was unable to move any further. The level of pain was now excruciating. Michael phoned an ambulance and I was taken to the local hospital.

The Local Doctor

The local doctor administered pain-killers immediately, which put me to sleep. I stayed in the hospital for a few days till I was able to go home, but within days of being at home, I awoke feeling so very nauseous, I vomited. Michael ran to the local doctor and asked to see him urgently. The doctor immediately organised my return to the local hospital. Blood tests were taken, and a
standby courier took the samples to the pathology clinic. The tests showed unusual and inconclusive results.

Further blood tests were taken to monitor kidney function. The results this time showed high calcium levels. This result, together with the orange colour of my skin and high levels of pain, was thought to be the result of kidney failure, which was caused by the toxic effects of tumours leaching calcium from the bones into the blood. X-rays were taken, and they confirmed the existence of widespread tumours. This was a life-threatening situation. Without intervention, the high calcium levels would lead to toxaemia, blood poisoning, a terminal condition. The doctor used a large 17 gauge cannula to flush fluids quickly through my kidneys, but this did not work quickly nor effectively enough. An oncologist was consulted for advice on how to reverse the calcium leaching. He prescribed Zometa, which had to be transported from a hospital 40 kilometres away. This drug did not have an immediate effect. The doctor said to Michael: “Unless we can reverse this, I’m afraid we are going to lose her.”

The Oncologist

The following day my health began to improve, and I stayed in hospital a few days longer - for observation and bed rest - till I felt well enough to return home. I then visited my oncologist 40 kilometres away. Michael now describes that journey as “a nightmare” – each bump in the road was an agony to me. On arrival at the cancer clinic, I was given a wheelchair, as I was unable to walk independently. The oncologist suggested I stay in hospital overnight and have a scan the next day.

This was not a pleasant night, because I was unable to rest. The nurses seemed so busy, they were generally inattentive and noisy – their station was next door to my bed, and they gathered there throughout the night to talk. One nurse
complained: “You are hurting me” when I squeezed her arm, as I flinched from the pain of moving. After the scan I went home. The oncologist ordered another scan and I saw him again for the results. In order to help bring my pain level down, he booked an appointment for me to see a radiologist, so that I could have radiotherapy for two very large tumours, one at the base of my spine and the other on the upper femur, my outer left thigh.

*The Private Hospital*

As radiotherapy was not available at any of the local hospitals, this was going to mean a two-hour trip to the nearest private hospital, that provided the treatment. Normally, the radiotherapy I needed is most effective over a period of six weeks, but considering my pain level and the distance involved, the radiologist decided he would give me intensive radiotherapy treatment over just three days, beginning with tattoos to locate the exact spots the radiation would be targeted. So, with lots of cushions around me, Michael drove me to the hospital two hours away. It was a very long, winding, bumpy road.

When we arrived I was taken to Reception, then to Radiology for the x-rays and tattoos. It was so excruciatingly painful to be lifted onto the flat bed, where the radiologist took the x-rays, but decided against proceeding further. We asked to stay overnight at the hospital and were told that there was an area for overnight stays. After settling in, I felt very ill. Michael called a nurse for assistance. He said that she took one look at me and wanted me moved to the Emergency Ward. This meant going back to the Reception area first. The receptionist said adamantly that I would not be treated unless Michael could pay $2,500 up front. A doctor and nurses arrived. Michael later told me the doctor looked very scruffy, very tired, and had his hands on his hips as he reiterated what the receptionist said. He refused to touch me. The doctor said
that I needed to be admitted, but he was not prepared to do anything unless Michael paid the amount. This was about two o’clock in the morning.

Of course, Michael could not give the hospital the money on the spot. This was an unexpected event, and, considering their attitude, Michael felt reluctant to pay them even if he could, because treatment would always be conditional on our ability to pay. The priority at this hospital, clearly, was not the patient’s health and well-being. Michael asked the doctor if he would at least give me something for the pain till he could find another hospital that would admit me. This request was refused. The nurses, on the other hand, were concerned and wanted to help, but under the circumstances, they could only suggest the name of the nearest public hospital that would treat me. The hospital they recommended was about 80 kilometres away. Michael was now extremely stressed. He was required to pay for a phone call that he needed to make to the public hospital, to let them know of my condition and the expected time of arrival.

*The Public Hospital*

Michael trailed the ambulance that took me to the recommended hospital. He now says that he could barely keep up, because they were doing 140 kms per hour on the freeway, to get me there as soon as physically possible. The paramedics put a drip up for me to ease the pain and to help me sleep. On arrival, I was taken into the Resuscitation Room. A doctor came in and asked Michael about my medical history. Michael said that I had breast cancer that had metastasised (spread) to the bones. The doctor immediately attended to my high pain level. He gave me 60mg of morphine, administered through a drip. Twenty minutes later, the doctor returned and before I was helped to sit up, he said: “I think she’s got pneumonia”. The doctor then also put an antibiotic for the pneumonia and an analgesic in the drip, which would give me a constant dose of morphine. He suggested that Michael should go home
and rest, as I was stable and would continue to sleep. He said that I was O.K. and: “Nothing life threatening now.”

The next morning Michael arrived, astonished to see me eating breakfast. The doctor wanted to keep me there, because the hospital could give me a room. He said that I had responded well to the antibiotics, and the pain was under control. He’d like to do some scans. Michael knew that I had already had a number of scans, and was worried about putting me through yet another ordeal. Michael asked the doctor to phone my oncologist. When the oncologist returned the doctor’s call, he and the doctor had a long telephone conversation. The oncologist decided he wanted me close by and in palliative care. Even though the hospice was about one and a half hours away from this hospital, they decided to get me there by ambulance and to admit me as a public patient. As Michael was on the aged pension and I was listed as a dependent, all this was going to be free of charge.

_The Hospice_

Our reception at the hospice was, to quote Michael, “F…’n brilliant. They made such a fuss. They knew exactly what to do.” The public hospital doctor had written “reams” of notes, and the hospice doctor was already there, waiting to examine and to admit me. The oncologist and intern joined her. This was about 6 pm. A pain-killing drug was injected into a cannula and again a drip was put up. Michael said that the nursing staff was so gentle in the manner in which they handled me and lifted me onto the bed. He could see in my response that I suddenly felt safe. He was told to leave, so they could settle me down. They expected me to be very drowsy for the next few days.
When Michael returned home that evening, he phoned my brother in Sydney to inform him that I was gravely ill and in palliative care, and asked him to pass on the information to all the family members. Michael also phoned our close friends.

On the following day he visited. Friends, who lived in the vicinity, also visited throughout the day. One stayed most of the day and was still there with Michael in the evening when he inquired about my condition. He was told that they did not expect me to be going back home.

During the 11 days I was a patient at the hospice, all my sisters and brothers visited me. I received flowers, and Michael brought me new nightwear, a beautifully coloured bed cover and my favourite things from home, so my environment would be cheerful and familiar. To everyone’s surprise, I became stronger. Michael then took me for walks in my wheelchair to the hospice canteen and around the gardens. When he eagerly and happily asked when I could go home, the nurses replied: “She’ll tell us when she’s ready.” As I’d been so glad to be there initially, I surprised myself when the day came that I finally asked to go home. The doctor was reluctant to comply, but at my insistence, made the necessary arrangements. My drug schedule was drawn up, and medical and social welfare agencies were contacted to support me at home. The doctor advised me strongly to have the radiotherapy I was not able to finish previously.

At home

Even though I was clear about my decision, I was at first very anxious about returning home, because of the safety I felt at the hospice. After a day or two, I settled back home and began to develop a routine that was conducive to living in a peaceful way. As I was not walking, my doctor arranged for an ambulance
to take me to the private hospital I had the x-rays, to have the tattoos and radiotherapy, as planned previously. The radiologist had decided to give me just one intensive radiotherapy treatment so I could return on the same day. This trip was free of incident, and the treatment worked, my level of pain subsequently dropped and I was better able to move. I needed to learn to walk again, but my biggest problem was my level of depression. My thoughts centred on suicide.
The Images and Stories

The images and stories in this RTA portraying my life journey with cancer are entitled:

- Origins
- My Family, My Culture
- Rag Doll
- The Demon Within
- The Silent Scream
- The Fighter
- Feather Inscape
- Slipping Away
- Living Horror
- Mother
- Morphine
- Heart of Peace
- Living in the Shadows
- Cancer (Mis)information
- Withdrawing / Emerging
Origins
Origins

This collage represents my way of being in the world when I was a child, a way of being that was inextricably related to my environment. My parents had migrated with their children from Malta (islands with an ancient and mixed cultural heritage, located in the heart of the Mediterranean). My mother’s was a traditional role inherited by women of her generation and persuasion: one of bearing one child after another, and of being forever tied to house and family. In Malta, she lived in a patriarchal society with strong Catholic beliefs and strong family loyalties, which served to imbed her in her oppressed way of life, tying her ever more tightly to her society’s culture and values.

She had given birth to thirteen children. Her workload was such that she could only attend to our very basic needs. She was constantly cooking, cleaning and sewing from morning till night, day after day, year after year. My father’s role in the family was shaped and conditioned equally by the patriarchal culture in which he lived. His career and identity was military; he was, in fact, a gunner in the Second World War. I expect that he endured the loss and suffering of family, friends and allies in the aftermath of the heavy bombardments the Maltese islands sustained (in fact, the most heavy in the world) – an experience, I believe, that both traumatised and brutalised him. His decision to migrate to Australia with the family came from his loss of job prospects some years after the war. He was also concerned about his children’s limited prospects in Malta and about keeping the family together.

In retrospect, I believe that the migration experience – which tore me away from the relatives I cherished, and a place and culture that were familiar to me – had much to do with the anxiety I felt when I was young. I turned four years old when we arrived in Australia. Another important factor was the dynamics that played out within my family of origin. I suspect that the war had a way of infiltrating the family experience. Under stress, there were feelings of rage
(expressed and unexpressed), blame and powerlessness. My siblings’ response
to this treatment was unordered, sometimes unpredictable and confusing.
Some (like myself) stayed on. Some ran away, and some disappeared. I
sometimes did not see missing sisters or brothers for years after they left home.
I was the second youngest, the twelfth child in this family. I stayed at home,
because my mother became critically ill when I was 13 and I felt an obligation
towards her, and because I had nowhere else to go.

As a younger introverted child, I hated the violence. I felt deeply troubled, but
powerless to change my family’s circumstances. At the same time, I so wanted
the pain to end. The emotions identified in this collage are shock, guardedness,
feelings of danger and of being burdened (with problems not of my own
making). Being quiet and invisible were coping strategies I employed to
survive what then seemed a chaotic and dangerous environment. I hoped that
if I did not draw attention to myself, then I would not be targeted for abuse or
punishment. The picture of the skydiver expresses a death wish. In my child’s
mind, death by suicide or by accident seemed an appropriate way out. I never
acted intentionally on this desire and no-one ever knew.
My Family, My Culture
My Family, My Culture

The Satir Communication Stances inspired this drawing. Family therapist, Virginia Satir, described the five main stances people take when stressed or under pressure: the blaming, placating, super-reasonable, irrelevant or congruent stances. My family of origin and the Australian culture I grew up in were both patriarchies. As such, masculinity and masculine values and characteristics were idealised. My experience of being female in the culture of patriarchy was primarily one of victimisation. Consequently, in this illustration, I am represented by the small crouched figure. This is a visual representation of the “placating” response.

The illustration of my cowering self is actually a photo. I took on the placating position physically, as described by Virginia Satir, one of fending off physical and psychological attacks. I coloured myself black, because I am undisputedly a part of this culture, albeit the part that is regarded as bad, threatening, untrustworthy, inferior and weak. I drew this originally to represent my place in my family of origin. More recently, I have come to perceive this as equally representing my encounter with certain aspects of the medical profession. For example, together with medical terminology, there is in scientific and medical literature, language drawn from military concepts and jargon. A leading cancer researcher likened the present treatment of cancer to “throwing a hand grenade at it and hope it kills more bad cells than good”. To pose a question: How different could medical treatment be, if instead of “blasting” the cancer, using “slash and burn” techniques, “fighting” and “killing off” cancer cells, “winning” or “losing the battle”, a very different conceptual model is used?

In the drawing there are figures doubled over. This posture represents the “irrelevant” stance. I associate the “irrelevant” stance with how I was feeling internally at the time I approached the medical profession for help. It was a feeling of collapse, of being drained of energy. This was my initial experience
of cancer. Yet, it was at this time, while I was feeling in a state of collapse and shock, that I was required to make important life and death decisions – urgently – about treatments. I knew better than to obey instructions blindly and to follow recommendations without question. I’d seen my mother and two adult sisters through their ordeals with cancer. Only my mother survived. I also knew better than to make the unconscious deals I’d seen others make, the tacit bargains made out of desperation and sheer terror by cancer patients with their doctors: “If I praise you and do everything you say, would you please, please make sure I don’t die. Would you please save me?” The doubled over stance then becomes one of mock reverence.

I had well-researched reservations about some treatments and refused them. My refusals were not well received generally. I finally found myself being labelled “a difficult patient”. This seemed to give medical staff permission to treat me with disregard and condescension. It is now clear to me why many cancer patients hand over their power readily: the (seeming) urgency of the situation, with little or no time to really think things through, the desperation and powerlessness one feels, and the very human (and Christian) inclination to look for a saviour. The sad truth is that some doctors too readily accept the power given them, when they cannot deliver honestly on their promise.
Rag Doll
Rag Doll
Rag Doll

This is an old drawing, which was rendered in response to an Art Therapy class assignment on childhood transitional objects. We were asked to draw our favourite childhood toy. I drew a rag doll in crayon with my non-preferred, left hand, so as to facilitate childhood expression. It is an imaginary doll I would have liked. I drew the image on black paper, without much thought. My memory of that time was mostly of feelings of sadness, aloneness and fearfulness. In a word-association exercise, I wrote variations of the description “limp”. I associate the word and image with the powerless I felt at the time. Also, a rag doll offers no resistance. As a child, I very often did not realise how much distress I was feeling. In retrospect, I believe this was because I had become accustomed to that way of being; it had become normal and natural to me.

I recreated inadvertently this highly anxious state in my work of choice and lifestyle later on in life. For instance, therapeutic work with people with drug addiction and domestic violence problems – while doing my Masters degree – seemed satisfying and worthwhile endeavours. At the same time, this overload proved detrimental to my health. One of the health problems I finally had was burn-out. By being present emotionally when engaging with disturbed clients, I suffered energetic contamination or depletion. I did not realise fully this risk to my health over a long period of time. Consequently, I did not provide myself with the self-care strategies that could have offset damage to my health and well-being.

I clearly had a pattern of being locked into situations, which were highly stressful. I am aware that while I was unable to escape my family environment, as an adult, I could have escaped a stressful work situation and an overwhelming workload. The point is that at that time I did not recognise my workload as being highly stressful and personally damaging. I believed
truly that hard work was very appropriate, very necessary, and very worthwhile, and that all my efforts would enable me ultimately to transcend my childhood legacy. I thought that if I finally landed on the “right side of the desk” as a counsellor, it was proof that I had succeeded in transcending my childhood patterns. On reflection, I was wrong. I did not realise that I was repeating a dangerous pattern of unconscious self-destruction.

In this drawing, I associate the doll’s attractiveness and open arms with my childhood need for affection and acceptance. The most distinct facial features are the large eyes and the relatively small mouth. I associate the wide open eyes with shock and fearfulness, also with vigilance and alertness. The small mouth indicates the reticence I felt. As I look at this image of an open-armed, wide-eyed, child-like figure with a torn and tattered dress, it seems a fitting symbol of my former childhood self in a distant, almost-forgotten past.
The Demon Within
(two images)
The Demon Within

These two illustrations are old images taken from a dream. This is an example of what I call a “healing dream”.

At the time I had this dream I was struggling with a situation I did not know how to resolve and it had been disturbing me for months. I had been humiliated and rejected by someone, who was important to me and I did not respond. At that point in my life, this was my usual way of dealing with this kind of interpersonal difficulty. I would feel ashamed, then I would remove myself from the “blamer’s” life altogether. The abuse was not deserved. Nevertheless, I tended to feel a sense of responsibility and would agonise about how I could redeem the relationship.

When I reflect on this, I can clearly see how my response – or lack of it – came about and how it became reinforced. As a child it was too dangerous for me to react to the abuse at home. To defend oneself, or to react with anger or rebellion, seemed to escalate the rage being expressed. (My actual response was to scream, a response that did not fit into any of these categories. The interesting thing was that it was at times effective, as the violence would stop.) The tendency to feel guilty, I believe, also comes from my childhood when it was necessary – or required of me – to take the blame. The need and desire for the difficulty to be resolved and for the relationship to remain intact is also understandable in the context of my childhood longing for peace, love and security. Understanding the childhood connection is, of course, not enough. Understanding alone does not offer a solution, that is, a way in which this recurring pattern in my life might be resolved skilfully. The solution came to me in this dream. It provided me with insights that helped me to put a stop to this habitual response.
The dream came two nights after I attended a weekend workshop with three skilled facilitators, two of whom were transpersonal psychologists. It was a weekend full of creative expression; we danced, played, created art, myths and stories. In the dream, I was with a group of people in an old castle, among trees, on a mountainside. We were tossing around ideas about the afternoon’s activities. Someone suggested horse riding. My immediate reaction was to dismiss the idea – I thought it too macho; in any case, I did not know how to ride a horse. Then, I noticed a strong, capable looking woman, an androgynous type, sitting on the floor with legs straight out and leaning comfortably against the wall. Inspired by her air of confidence, I found myself reconsidering my stance – perhaps I could learn to ride a horse. (This, I think, represents an invitation to learn to be skilful instead of going with my “natural” inclination.)

Suddenly an announcement was made: the devil was coming and he was due at any time now. A silence fell on everyone in the room. They quietly went into a larger adjacent room and formed a large circle, several rows deep. The room darkened, the atmosphere was very intense, the mood sombre. We were waiting in suspense for this awesome power to arrive.

During this time I found myself wondering how best to deal with this situation. I wanted to make the most of this encounter. Then, suddenly, the huge castle door creaked slowly open. The devil came vaguely into view. I thought I saw a skeletal figure in a blur of orange and white against blackness. When he came in people crowded around him. I could barely believe what I saw; I circled the crowd to get a closer look. It was the figure of a mendicant, stooped and humble. He was going around the circle to each person asking, begging their forgiveness. It occurred to me that he looked very much like the abbot of a Buddhist monastery and lay community centre where I once stayed. I decided I definitely wanted a personal encounter, so I made my way through the crowd towards him. He finally looked straight at me. Nothing had changed. Without moving his eyes, he spoke to me with great awareness, and great presence. He was anxious and repentant. He said: “I am very sorry.
Please forgive me.” Suddenly, I saw in front of me all the significant men in my life, with whom I had experienced hostile or conflicting encounters and with whom I was left feeling humiliated and worthless. All were now in my presence asking, begging for my forgiveness and treating me with great respect – as if I mattered greatly to them. Being treated with genuine respect by these men was strange to me. It was a very moving and healing experience.

As I reflected upon my interactions with these various men in my life, I realised very clearly that they were men of a particular type. I came to understand that their abusive, unjust treatment of me was based on their tendency to blame others (women) for their own mistakes and personal limitations. In other words, I was – consciously or unconsciously – their scapegoat. The abbot, I knew, was inadvertently such a man. He was a monk of the Theravada Buddhist tradition, who had stated publicly that a woman is more dangerous to a monk than ten thousand tigers. This statement was presumably meant to protect a monk’s celibacy, but it is a misleading statement. It is dishonest ultimately, and harmful to women both individually and collectively. In truth, it is not women (or men), who are dangerous to celibates, because of their natural sexuality. It is the feelings of craving that arise within a person, which can be dangerous, and which should kept in check. I knew instinctively such a man was not a true ally, and yet this was an abbot, a man of authority – like my father, one I was conditioned to honour and treat with respect.

The insights I gained from this dream have enabled me to face people of this type. In their presence, instead of abjectly disappearing from view hoping to avoid abusive treatment, I now respond very differently. I no longer want to appease offensive men (or women). My intention now is to redeem myself in my own eyes, to behave with self-regard and dignity, and to act with integrity, knowing that I am not responsible or to blame for the feelings of discomfort, inadequacy or shame that arise in others.
I think this was the turning point in my behaviour towards abusive men, and in particular, those in positions of authority in this patriarchal culture – some medical (and alternative) practitioners, for example. When I now treat doctors with respect, it is not automatically given, because of their gender or their professional status. I look beyond the person’s role and appearance. I am cautious generally and I make a point of taking personal responsibility for any decision about my treatment that may be made, because I clearly know that there may be a conflict of interests. Some doctors today are not yet holistic in their knowledge and methods, and they are essentially people in business. This being the case, medical treatments are limited in their scope, and medical practitioners’ ethical conduct may be compromised.
The Silent Scream
The Silent Scream

This illustration came to mind when I remembered the reality of being afflicted with metastatic cancer – a disease that had progressed to the point of imminent death. I mention in the commentary of the illustration entitled “The Fighter” that my night time experience of living with metastatic cancer was horrific. This illustration depicts the daytime reality. This is about the anguish of knowing my predicament consciously; of being aware absolutely of what is happening to my body, to my mind, and to my spirit.

Looking at the illustration, I notice that the eyes are closed. On reflection, this represents a looking inward, looking within, connecting with my inner reality, my feelings. At that time, my feelings were multi-layered. The pain related to both physical and psychological agony. I describe the pain as agony, because of the intensity of the feelings involved. In this illustration, the demeanour of the figure suggests one who is calling, in a desperate call for help. Alternatively, the mouth is open to produce a scream, but it is a scream that is not heard.

In terms of the physical suffering, there was – primarily – the ever increasing pain; the tumours were in my bones at various points and in varying sizes throughout my skeleton. There were also multiple tumours in the soft tissues, and some could be felt beneath the skin. In addition to the tumours, there was the mutilation of the body – the surgery and its consequences. I became aware that from the time of the surgery onwards I would have to worry about the reality of living – every day – with physical discomfort and the dread of disproportionate swelling, brought about by the removal of lymph glands. I had expected the “experts” to give me all the factual information, and to alert me to these potential effects. They did so in full, only after the surgery.
The psychological impact was equally distressing. The primary feelings were one of helplessness and grief: helplessness at my perceived powerlessness to do anything about this situation; and grief, inconsolable grief, over the losses I’d already experienced and over the losses I was in the process of experiencing. Losing my health and my ability to function in the world was not only unimagined by me, but also the source of great sorrow. I could not do those simple things I used to take for granted: I could no longer sit, stand, walk, or enjoy listening to music or reading. I could no longer earn my own livelihood. I’d lost my career, my life’s work, and with it the opportunity to apply the skills, which I had spent many years at University and in the workplace to cultivate.

Michael and I had left the home we had made for ourselves in the 16 years we lived in Perth, and with it some dear and cherished friends. The greatest sorrow I experienced – apart from the loss of my health – was the impending loss of my primary relationship with my husband, Michael. Our relationship of mutual support had changed dramatically to one of my dependence on him. The prospect of losing him completely, his love and his physical presence was very, very painful to me. At the same time, I witnessed Michael’s suffering, his own distress at the prospect of losing me, at the prospect of losing our relationship – the one source of true love, peace and joy in our lives.

When I look back on this time, I remember vividly seeing the pain in Michael’s eyes; the look of pain that was very hard to behold, and very hard to bear. I also remember my response; I felt responsible for his suffering. Yet, there seemed little I could do to change what was happening. Nevertheless, I made a resolve, a promise to myself, that I would do anything I could to lighten his load. Certainly, there were times I felt I could easily slip away, and there were times I truly wanted to. At those times, life had become so painful, so tragic, that death seemed a merciful release. Equally, there were times I made extra efforts to overcome the crisis I found myself in. I think this is one of love’s
greatest strengths. Love inspired me to overcome my difficulties, even those difficulties that seemed impossible to overcome. There is now one thing I can say without a doubt: that love created the turning point, the motivation and path towards healing.
The Fighter
The Fighter

When I was on large doses of morphine (200 mg daily), my sleep was full of nightmares. In my dreams, I was shot, punched, kicked, knifed; I experienced tsunamis, landslides, earthquakes, and volcanoes erupting – the many variations of catastrophic and apocalyptic events. Night after night, these dreams would come, and I would invariably wake up in panic. That was the first time in my life that I experienced panic attacks. I would wake up with a start and shake uncontrollably. I was also weary and constantly terrified. I dreaded the prospect of living another day, of sleeping another night.

This illustration depicts a figure in one of my dreams. He was a hefty man in the process of punching me. His intention was to knock me out. His demeanour was fierce and determined. I was repulsed by him. At the time I was having these nightmares, I felt overwhelmed by what I was experiencing. My reality by night and by day was filled with horror.

These nocturnal images were accompanied by feelings of helplessness. Very often, I would wake in the middle of such dreams. I was left with clear images of unrelenting aggression in my mind, and with feelings of devastation.

As I reflect on this image, I see that it represents my experience of cancer, at that time. It was an aggressive, seemingly unstoppable form of cancer. There was a very real prospect of losing my life to it. I felt overwhelmed and overpowered by it. I perceived the cancer at that time as being far too strong, too fierce, and too aggressive to overcome. I felt my hope for a recovery was now futile. I was both terrified and horror-stricken by its destructive effects on my body, mind and spirit.

It is significant to me that I did not sense – however great the battle or struggle – that the “enemy” in my dreams was the final victor. This might suggest that
in my battle between life and death, I was not altogether convinced that I would not survive. I am also aware that this image came from my body/mind/spirit. I suspect that I am looking at a mirror image of an aspect of my own self. In this sense, the creation and creator are one. “The fighter” – ultimately – is the fighter in me.
Feather Inscape
Feather Inscape

This is an old drawing. It is a landscape that still comes to mind, particularly during difficult times. This image was rendered many years ago, when I was doing a Masters degree in art therapy, following an exercise set in class. We were to use an image of a symbol of the self and to create a landscape equivalent in nature.

My symbol at the time was a feather. I chose the feather as my symbol after noticing that I frequently used feathers and associated images and themes in the art therapy journal I created. I used the feather as a symbol, which related to a bird. To me, it was a symbol of transcendence, which inspired larger vision and spirituality. My supervisor at the time said that there are other qualities that are also suggested by my symbol. He said that in my work as a therapist the symbol of a feather suggests that I could help clients find their lightness, their softness and their freedom of spirit.

On reflection, my supervisor’s comment was more significant than I then realised. I remember that, at that time while I was doing my art therapy degree at Master of Arts level, I was working professionally on an outreach, home-visit basis with women (mothers) with drug addiction and other major problems. It was also the end of semester at the University and I was in the process of finalising and handing in work for assessment. My combined workload was weighing heavily on me and I desperately needed a break. I imagined the kind of place I was drawn to for a holiday and this particular image came to mind – a place in the sun, close to the sea, in the stillness and beauty of sunset.

Coincidentally, the image that came to mind was also to me a landscape, equivalent to the symbol of a feather. The qualities of lightness, softness and a freedom of spirit, which my supervisor suggested were associated with the symbol of the feather, were the antithesis, the exact opposite, of how I was
feeling personally at that time. While my supervisor framed the qualities of my symbol as those qualities I could offer as a therapist, they were also qualities I needed to develop and feel in myself. As I reflect on this, I now realise that the image of a feather so accurately symbolised what I most needed, what was missing for me at that point in time. These many years later, I can now see that this insight was the whole point of the exercise. I chose instinctively the symbol of the feather, which represented simultaneously certain qualities that I already possessed, as well other qualities that I needed to develop – my potential qualities, my limitations.

I recall that during times of great distress and difficulty in my life, this image has consistently come to mind. It is a comforting image, which engenders a sense of peacefulness, contentment and harmony. It occurs to me, as I look at this landscape more closely, that there is not only a consistency in the way I create this image in my mind during times of stress, but there is also a sense of familiarity and a significance about the image itself and the feeling of longing associated with it. Ultimately, I sense that this is not a created image, an imagining. It is more a memory. I am remembering my homeland, Malta, my birthplace – islands in the sun, being close to the sea, in the stillness and beauty of sunset.
Slipping away

This is an illustration of a dream involving myself and two older sisters. I dreamed about my sisters as I remembered them, when we were children.

In the dream, we are in a small room, which is suspended high above the clouds. The room is much like a large cardboard box, the sort of thing we used to play with as children. My sisters were talking in a friendly and relaxed way. Even the one seated right on the edge of this room high in the sky was relaxed and smiling and not at all concerned about falling out. I, too, was right on the edge, but unlike my sister, I was terrified. I felt myself slipping off the edge and I was desperately trying to hang on. One of the most curious things about this situation was that neither sister was frightened, and neither sister seemed to relate to my panic. I wanted them to help – or to at least know of my predicament – but I was unable to communicate my distress. There was a strong wind that made it difficult to breathe or to speak. I also realised that from their perspective my distress was not apparent. My terror mounted as I felt myself slipping off and struggling to hold onto the sides of the room. A fall meant certain death. I awoke suddenly from the dream in a state of panic.

This dream represents my state of mind at that point in time, when I believed that death was imminent. In reality, these two sisters were at that time struggling with their diagnosis of breast cancer. Their relaxed state of being could be interpreted as either their acceptance of their situation, their being at peace with it, or alternatively, their being unaware of the potential danger. Another possible interpretation is that they appeared relaxed, because they were, in my view, safer than I was. Their cancers were primaries, whereas mine was considered to be secondary – which meant that it had already spread. So much so, that at the time of this dream, death was a distinct possibility and the dream a true reflection of my reaction. My two sisters’ inability to see the
distress I was in is related to my inability – or perhaps unwillingness – to communicate my distress.

This is reminiscent of my childhood demeanour, when it seemed futile to communicate my difficulties. As a child, I sensed that in spite of our outward behaviour (which was very different), we sisters shared the same inner experience. We shared the same sense of anxiety, injury and hardship. Today, none of my aunts or other relatives in Malta has cancer. Yet, by the time of this dream, six women in my immediate family had been diagnosed with cancer – my mother, myself and four other sisters. None of my four living brothers had developed cancer. On reflection, the illness was not all we women had in common. Most significantly, we had all experienced much distress – primarily the result, I believe, of having been subject to the effects of war, displacement, loss of home and country, and the pernicious effects of the aggression within patriarchal cultures on women, that is, the belief systems and behaviours, which do not truly value our existence, nor honour, respect and nurture our essentially female natures.
Living Horror
Living Horror

This image comes to mind when I recall my demeanour, when I was critically ill and expecting to die. At that time, I was thin, and unable to eat. I was aware of the fact that I had metastatic cancer, that had now spread throughout my body (represented by the red spots in the drawing). The largest tumours – on my thigh, lower back and shoulder – created lumps, that could be seen and felt through my skin. The doctors’ efforts now seemed futile. There was no relief, no escaping this reality. In this image, the female figure represents me at this time. My demeanour is one of utter terror and horror. I am bound by rope to convey the paralysis I felt, and I was unable to move, unable to escape. Any movement at that time was excruciatingly painful, so I lay quite still. In spite of the morphine I was taking, I was conscious of my circumstances – that I was critically ill, that Western medicine was ineffective at this point, that I was about to die at any time, and in a horrible, dreadful manner. There had already been some close calls, and finally there would be the bullet that was aimed to kill. I would die the victim in life’s macabre game of Russian Roulette.

As I reflect on this illustration, I notice some features that reveal truths that were not drawn consciously. For instance, neither my hands nor feet are drawn. The omission of hands indicates to me the powerlessness I felt at the time; I felt unable to do anything at all about my situation. The omission of legs and feet describes my actual inability to move, to stand and to walk. I interpret the image of the gun pointing at my head as imminent and sure death. I also see it as a metaphor for the need to bring to an end my conditioned inclination to relate to my life and the world predominantly “from my head”, that is, from my thought-processes and intellect alone. There is no figure attached to the gun pointing at my head. In my mind, the figure is definitely masculine. It represents the aggressive, destructive and exploitative aspects of patriarchy.
This, for me, was ultimately a transformative and life enhancing event. I allowed myself to experience fully the feelings I had at the time – I was paralysed with fear, threatened with the real danger of losing my life, feeling extreme pain and futility. From this immersion, I noticed a sense of familiarity – I had experienced these feelings before. They were there in my childhood. I was shocked by my sudden discovery, that in spite of all my determined lifelong efforts, I had never truly transcended my childhood legacy. I had never really found the true peace of mind I had so longed for. My whole life had been one of struggle, full of effort to overcome my difficulties. At that point of realisation, I experienced profound and heart-felt compassion for myself, for the hardships I had endured, for the never-realised goal I had set for myself. I had believed wrongly that peace was something I would achieve in the future (after much hard work), however, as such, it remained in the future. This was a profound insight, one not understood merely by the intellect. It was an insight that I experienced with my whole being. I finally, profoundly, completely, understood.

This insight led to my consciously choosing a different way of being in the world. My previous focus on “doing” things (to overcome my difficulties) was clearly mistaken. My state of “being” was now paramount – a truth I had neglected unknowingly all my life, until then. Even during this very difficult and (seemingly) very late stage of my life when all seemed hopeless and futile, when I was racked with pain believing that I would not survive, I decided to live my life – however much longer it was to be – in the way I had always wanted to live it. I had believed previously that I had to struggle hard to overcome my difficulties, that I had to earn peace of mind and freedom from suffering. Everything in my culture seemed to support this delusion. I saw finally my life’s mistake clearly. I finally understood deeply – when I believed it was too late – an adage of profound wisdom and compassion: “There is no way to peace – peace is the way” (A.J. Muste).
Mother
Mother

This is an image of my mother. When rendering this image, it was the very first time in this collection of illustrations that I did not reach automatically for a black coloured background, on which to draw. This image of my mother’s face is associated with light and warmth. This was one of the images that sometimes came to me after a series of nightmares, when I was critically ill. The effect was profoundly soothing and comforting. The disturbing effect of the previous dreams was diminished to virtual non-existence by my mother’s presence. Sometimes, her image was accompanied by a short dream involving my family of origin, and included happy events with my deceased sisters. When it came, this face was always the very last image in a series of dreams, as though it was intended to be so.

I associate this image with the very last time I saw my mother alive. She experienced a prolonged death in a nursing home. It was such a sad death, at the age of 80, after bearing thirteen children, leaving her own mother and sisters in Malta to migrate to Australia, surviving uterine cancer, the deaths of two infant and two adult children, and finally, the death of her husband, my father. I was living in Perth at the time she was dying, and I came to Sydney for a week to see her. She died a day or so after my visit, when I left again for Perth. It seemed that she had been waiting to see me to say good-bye. I remember the very last look she gave me. She was very weak and unable to move or speak at the time. The look was of profound love.

As I gazed into her face, I understood her in a way I was not able to in my younger days. It was difficult for me to communicate with my mother when I was living with my family of origin. There was so much I did not understand. My questions were often not answered satisfactorily, so I stopped asking them. I became a reticent and withdrawn child. As far as I could, I found things out for myself, and worked out my own problems. My mother belonged to
another time and to another culture. There was a mismatch between her Maltese culture and the new Australian culture, which I was meant to assimilate. I learned to speak English exclusively and to go to Australian schools. At school, I was put immediately in a kindergarten school class with other “foreigners”, not in Class 2A or 2B with my Australian contemporaries, but Class 2“O”, with other immigrant children. The effect was that I did not have a sense of true belonging to either the Maltese or to the Australian culture.

My otherness, my being different, was reinforced consistently. Even when my marks earned a place in the “A” class (within a year or so), I was still ostracised and called derogatory names by other children; I was still treated with hostility and suspicion. As I look back at the context in which this was happening, I remember that it was the time of the “White Australia Policy”. I have no doubt at all that such a racist policy contributed greatly to how I was perceived by my “true” Aussie classmates. I envied their sense of belongingness and safety. I envied, too, their apparent closeness to their mothers.

The tenderness on my mother’s face at the nursing home filled instantly the gaping holes in our relationship. The awkwardness of our past relationship dissolved completely in that one look. My difficulties and anxieties all seemed to disappear. So much so, that I was inspired to look within, to discover how to look upon myself in that deeply healing way, the way I always wanted and needed to be looked at (and treated) – with such kindness, such respect, and such love.
Morphine
Morphine

This self-portrait expresses my state of being, when I was on large dozes of morphine to counteract the pain from multiple malignant bone tumours. I remember vividly the overwhelming drowsiness and the constant, difficult struggle to stay awake. That was coupled by a certain longing for a peaceful and deep sleep, for oblivion, an escape from this brutal reality.

When morphine was first administered, I remember receiving it gratefully, as an act of mercy. At that point in time, every movement was painful, so much so, that I lay quite still. The subsequent side effects were endured necessarily: being startled awake by the inability to breathe; the deep, dark, sometimes suicidal depressions; daily panic attacks and nightmares; an inability to distinguish between wakefulness and dream states; severe constipation, and so on. The most dreadful consequence of being on morphine was my awareness of the long-term implications. The morphine was only palliative.

There was a dichotomy about my state of being during my illness. Though I looked physically weak, I was aware mentally of both my internal states and my surroundings. In fact, I was more sensitive than usual. I could perceive clearly acts of kindness. I was aware equally of acts of aversion and hostility. For example, I remember - with gratitude - the care I received from a particular doctor, when I was admitted into the emergency room of a public hospital, also the kindness of the doctors and nurses I encountered when I was then admitted into a local hospice. I suddenly felt safe. This was in sharp contrast to how I felt in response to the treatment I received at a private hospital just previously.

I had arrived at the private hospital to receive radiation treatment, which was delayed subsequently. During that night before the procedure, I became very ill at the hospital and I was unable to move, because of the pain. On request,
the nurses helped Michael move me to the Accident and Emergency section immediately. The doctor on duty there refused to treat me, insisting that Michael pay the hospital fee of $2000, before he would do anything at all to help. The receptionist supported the doctor’s decision and refused my admission. Despite the attending nurse’s protests and expressions of concern, the doctor again refused to at least treat the pain. This was in the very early hours of the morning, a life-and-death situation, and they refused to act.

I am still stunned by the memory of this. Most of all, I am shocked that the doctor present at that time was somehow able to justify this unprofessional, insensitive and unethical behaviour. I may have been unable to move and respond, but I was aware painfully of what had happened. I remember what was said. Michael understood that his own response to this situation was to be based not so much on whether we could produce the money on demand, as to whether he was prepared to entrust this hospital’s staff with my health and well-being. Their highest concern seemed to be monetary. Panic set in, as he saw the hospital staff stand by idly, while my condition became increasingly critical. Michael decided quickly that he had to take me elsewhere. He asked the receptionist for the use of a phone to call an ambulance and the nearest public hospital. The receptionist asked for the money (for the cost of two phone calls) first. A skilled doctor at the public hospital I was then rushed to, diagnosed my condition as pneumonia and widespread bone cancer – probably the outcome of late stage breast cancer. He immediately, mercifully, gave me 60 milligrams of morphine for the pain.

This self-portrait shows a hint of a turquoise blue pendant, which one of my sisters gave me to wear. The pendant depicts an image of the Madonna and was said to contain miraculous water from Lourdes. While I instinctively understood my sister’s (and other people’s) need to inspire hope in me, at that time, it was very difficult for me to maintain any religious belief or faith. The pain and suffering were overwhelming and unrelenting. At the same time, I
had a constant, urgent need to sleep. In terms of the conventional understanding of God, I felt a sense of complete and utter abandonment.

If a powerful, benevolent and healing force does exist in this universe, it became apparent in the kind and loving actions of those family members, friends and strangers, who did not turn away from me during this most painful and desolate time in my life. I remember the people, who visited from near and far, the unexpected gift of money to help pay my medical expenses, the home-cooked meals and boxes of fresh home-grown vegetables that arrived at the door-step, those who held my hand, those who held me in their hearts and in their prayers, and the warm, encouraging smiles on faces known and unknown to me. Some of these people, who offered their help and support during this time, had religious or professional affiliations, and some did not.

Michael was my most constant and dependable companion. To this day, I am in awe of his courage and loyalty. I can barely understand how he made the decision to stay, and how he kept making that decision – from one catastrophe to another, from one day to another, from month to month, and as it turned out, from year to year. It is hard to imagine how he was able to endure and to survive the ordeal, given his almost total isolation, and the length and seriousness of my illness, with its huge physical and emotional demands.

I can now understand how others can abandon their partners, family members and friends in similar circumstances. I believe it is essentially a matter of self-preservation. From my perspective, Michael and those who are able to stay in the midst of “the molten chaos” and the “living grief” of a beloved’s dying, do so from a place of selflessness, one of unconditional love and compassion.
Heart of Peace
(two images)
Heart of Peace

During my hospitalisation and afterwards when I came home, I found it difficult to sit formally in meditation. For one thing, I was unable physically to assume the posture. Even when I was finally able physically to sit in meditation, the level of morphine I was taking meant that I would inevitably fall asleep, consistently, every single time. At first, I fought the inclination, then I realised it was futile. I clearly needed to rest.

Instead, I assumed a posture in my mind, a mental attitude I adopted to cultivate the feeling of peacefulness within. This was extremely important to me, because my life had become the lived experience of horror, pain, exhaustion, of grief and utter misery. I needed to counteract this overwhelming aspect of my reality with a practice that enabled me to transcend my physical and psychological reality. At any given time, I would close my eyes and breathe in health and well-being, and breathe out weariness, distress and disease. My attention turned inward toward my heart chakra (energy field), and I focused on radiating a feeling of loving kindness towards my physical body.

In the first illustration, the radiation of loving kindness is depicted in pink, a colour associated with unconditional love. The colours of the clothes I am wearing in the illustration are colours I wear normally at home. The clothes suggest the need for protection and safety. I chose a deep velvety blue for the colour around my head. It was the first ball of colour I saw when I first began to see auras, perhaps the colour I most resonated with at the time. The blue was dark and a beautiful, soft, luminous colour.

In the second illustration, both heart and head are illuminated. I learned from the insight into my need for true peace, that the concept “peace of mind” is an inadequate one. The concept “peace of mind” maintains effectively a
separation between mind and body. My previous efforts to create and develop peace of mind, ignored the needs and feelings within the body. On reflection, I believe a major cause of my illness was that emotional distress was being dealt with on a physiological, rather than on a psychological level. I now view the state of peace as both physiological as well as psychological. The feeling depicted in both illustrations is one of stillness and centredness. It is a core of peace in the eye of the storm.
Living in the Shadows
Some time ago, the facilitator of a local cancer support group phoned me at home. She asked me to visit a young woman (aged 41), who lived in my neighbourhood and was critically ill. This young woman had refused an invitation to attend the local support group, because she felt uncomfortable about attending a group with women much older than herself. I was the youngest of the group (53), thus closer to her age. The facilitator believed that my experience of surviving a critical illness might encourage her.

Though I agreed to visit this young woman, I noticed my resistance, which was a certain reluctance. It may have taken two weeks before I finally rang the bell at her front door. An athletic young man with a shaven head answered, and there was wariness and distrust in his demeanour. I recalled seeing him on a number of occasions, walking the streets with a wooden staff in one hand and the collar of a large German Shepherd in the other. I introduced myself and explained why I had come. There was a voice and the sound of movement coming from the adjacent room. Only then, I was ushered in.

From the shadows came a voice, then finally the figure of a frail young woman. She was thin, emaciated. She wore a scarf over her (hairless) head. She could barely speak. Her lips were peeling. She explained that she was undergoing chemotherapy and had an ulcerated mouth. There were also growths in her neck that prevented her from swallowing food. She was quiet and still. I sensed her dark mood, her deep depression.

I addressed her automatically by the name I had been given, “Stacey”, but I noticed that the young man, Salvador, called her by a different name. After a time, Salvador left and Stacey made some tea. Her home environment was immaculate. It was a small wooden cottage surrounded by neatly clipped trees.
and a garden. The side veranda had a sitting area, which overlooked a gully hidden by wilderness.

Stacey told me that she was adopted as a child, and that her new mother gave her a different name. She had a twin brother, from whom she was separated long ago; they were each given to different families after the death of their natural mother. Stacey spoke of a traumatic childhood, of a very difficult relationship with her new parents. She was convinced that her adoptive parents knew the whereabouts of her twin brother, but they resolutely withheld the information from her – even now. She longed to see him again. Salvador called her “Brianna”, the name her natural mother had given her. She preferred to be called by that name. It was the one link she still had with her real mother.

Brianna also spoke of her illness. After receiving her test results, she asked her oncologist for his opinion, to “give it to her straight”. She said that he told her: “You are going to die”. Her mother was there last night, telling her the same thing, over and over: “You are going to die”. She also criticised Brianna – loudly – for her involvement with Salvador; she judged the relationship as sinful. I now understood why Brianna was so despondent.

Brianna then spoke about Salvador. She had only recently met him. He had moved into a unit next door and they developed a friendship. Salvador was health conscious; his physique was slim and muscular. He brought her herbs and foods, that he believed would build her strength and give her energy. In spite of his attention, Brianna felt cautious about becoming involved with him. She explained that her (second) husband left her last Christmas. He abandoned her when she became very ill. She was worried that this new relationship was developing too fast, too soon after the separation.
There was much pain in what Brianna said. The only time her facial expression eased was when she mentioned Salvador. The break-up with her previous partner had evidently been painful; that relationship was over. I could understand her attraction to Salvador. He seemed to be the only person in her life, who was giving her any measure of companionship and comfort.

Brianna became relaxed increasingly and peaceful in our two hours together. I left realising that this could not be a one-off visit. Brianna needed ongoing support. I now understood my initial reluctance to make this visit: I was feeling drained of energy, absolutely exhausted.

Immediately on my return home, the phone rang. It was my friend Mellie, and there was urgency in her voice. She wanted my advice on how to relate to her friend, Caroline, who was just given the devastating news that she had widespread cancer. Caroline was in her early 50’s. She was a shiatsu practitioner, and I remembered Mellie speaking very highly of her skills. The hospital staff had apparently awakened Caroline during the previous night to tell her the news of her condition, also to urge her to begin chemotherapy as soon as possible. Caroline was in a quandary; she did not know what to do. Mellie was on her way to the hospital to see her, and she was clearly in a state of panic.

I told Mellie that I was just about to have a rest and that I would talk to her at length later on. For now, I wanted to express a couple of thoughts that had come immediately to mind. I suggested that if Caroline wanted to discuss whether to undertake chemotherapy treatments, it was important that she made an informed decision, one based on all the best information available. For instance, did Caroline understand clearly why she was being recommended this treatment? What were the medical staff hoping to achieve, and at what cost (to Caroline’s body, mind and spirit)? How had others with a similar condition fared with this treatment? Was Caroline aware of other
options? Did she need more time to make a decision? I then addressed the issue of how Mellie might relate to Caroline. I counselled Mellie against asking Caroline how she was feeling (it was evident). I suggested that she might simply be present for Caroline as a friend, to listen deeply to her and to respond to her concerns appropriately. Caroline was more likely to make the right decision for herself in a clear state of mind, rather than in a state of shock and panic. Mellie seemed satisfied with this response and hung up. I then went straight to bed.

Around this period of time, my brother and a friend also contacted me about helping people they knew who had medically incurable illnesses. I began to feel uneasy increasingly about this new role, that was being thrust upon me. My inclination was to decline these requests. I felt intuitively a disinclination to become involved. Counselling someone with a brain tumour, who was given months to live, for instance, needed time and care; it was clearly not going to be a short, single conversation. Moreover, it was painful vicariously for me at that time, to be reminded of the ordeal I had just experienced recently.

After much consideration, I decided to refer such inquiries elsewhere. I realised I was slipping back into my old role as a counsellor, one that I was trained for, but no longer wished to pursue – at least, not at this time. Other people, like Petrea King and Ian Gawler, had written books about overcoming medically incurable illnesses, and held groups and retreats on an ongoing basis; I would refer people to them. I felt the need to focus on myself, on my own health and well-being. So, I wrote Brianna a letter explaining that I could not see her on an ongoing basis. I wanted her to know about a local group, whose members were trained in palliative support care; I would introduce her to a group member I knew, whose presence was uplifting and in a similar age group. I also phoned the cancer support group facilitator and told her that she was asking too much of me at this point in time. My contact with Brianna
could not be on a single-visit basis; she needed someone who was able to “hold” her in the sense of being able to give her ongoing support.

Nevertheless, Michael and I went to Brianna’s home. I really expected she would be too ill to receive visitors, but I did actually talk to her. She and Salvador were about to leave to attend an auction, at which Salvador hoped to sell his motorbike – he wanted money to pay for a trip they were going to take. Salvador knew of a retreat centre in Melbourne, which was run by a renowned practitioner of Traditional Chinese Medicine; he was convinced that Brianna would find help there. Brianna wanted to sell her car to pay for the trip, but Salvador insisted on selling his motorbike. He knew that Brianna needed her car; it was her only means of transport.

Brianna showed me her neck. There was an area above her left collar bone that was swollen massively. The distraught look in her eyes confirmed my suspicion that this was a tumour. I asked Brianna when she had first noticed it. She said that it appeared during an argument with her former husband, just recently. There seemed to be a message in this. I suggested that it might be related to her anger, that she may be able to heal it with the antidote, the opposite emotion. “Send it love. Give yourself love,” I said.

I managed to slip her my letter of withdrawal, but I also promised to see her again later that day. I remember Michael asking her if there was anything she needed. “Life,” she said. Brianna phoned me later that day when she returned from the auction; she wanted to cancel our appointment. I realised from her tone of voice, that I had made a terrible mistake. I needed to make amends, urgently.

I went to see her the next morning and stayed a while. I apologised for my insensitivity; I would see her when I could. I then gave her a copy of Petrea King’s book entitled “Quest for Life”. We then talked about her upcoming trip.
Brianna was feeling somewhat apprehensive about it. At the same time, she sensed that this was her only hope, and she felt encouraged by Salvador’s unwavering support and optimism. Later, I introduced her to Pat, a member of a palliative care support group in our town.

Brianna and Salvador visited me at home just before they went to Melbourne. They left me with a basket of fruit and vegetables, and asked me to look after their mail while they were away.

About seven weeks later, I noticed Brianna’s car in the carport – she and Salvador were back. Brianna was looking radiant. It was a total transformation. She told me happily that she was feeling much better. She showed me the lump on her neck; it had remarkably reduced in size. She said that she could now walk up the steep hill behind her property and down to the river with Salvador. She had barely been able to walk around her house and yard before she left for Melbourne. While she was at the retreat centre, she had adopted a complete lifestyle and attitudinal change. She had started meditating and doing Qigong exercises for hours every day. She was following a prescribed diet and using Chinese herbal supplements. She was full of energy and optimism. I discovered that she wanted to have a baby, and subsequently became pregnant, with twins.

I saw her once more. Then, I received a phone call from Salvador one Friday morning. He said that Brianna maintained her well-being until her ex-husband and family members went to her home. They treated her as if she was dying and came to stake their claim on her property. Their ensuing arguments and negativity extracted a heavy toll on Brianna. Her health began to decline rapidly. Salvador had phoned to let me know that she had been taken to her parent’s house, then to a hospice. She had reverted to the name she was commonly known by, “Stacey”. She was refusing visitors.
This news was so unexpected and so tragic, that I was overwhelmed with grief. My first thought was to send her flowers with a card, which included my telephone number. The news was also confusing. Why had she left Salvador? Did Stacey go willingly to her parent’s house (given her family history of trauma and abuse)? The florist phoned me late in the afternoon to say that Stacey was no longer at the hospice. She had been transferred to her parents’ home. The florist offered graciously to take the flowers there on the following morning.

After the weekend, I phoned her parents’ home, realising the need to use tact and diplomacy. Her mother acknowledged receipt of the flowers and explained that although Stacey told her that she wanted to phone me, she did not have my number. In any case, Stacey was on high doses of morphine and was generally too weak to make the call. I thanked Stacey’s mother for the information, left her my telephone number, and asked her to let Stacey know that I had phoned.

On Wednesday morning, I went to the local hospital to talk to a community nurse, who I knew well and trusted. At this stage I had not received a phone call from Stacey or her parents. I was unsure how to proceed with this situation, and had some doubts as to whether to persist. The community nurse told me that she was bound by patient confidentiality, so she was limited in what she could say. She admitted to also being concerned about Stacey, because Stacey had refused all help – even palliative care from the community nurses. The community nurse recommended that I persist in my efforts to contact Stacey, because I may be the only person she would see.

Salvidor later phoned me at home, to tell me that Stacey had been taken to the local hospital. He had tried to see her there, but was refused entry by her parents. Nevertheless, he forced his way in. He managed to see Stacey and to exchange a few words. He now wanted me to ask her a question on his behalf:
did she want to see him again? Before I had a chance to ask him why she was refusing to see him, he confessed that he had argued with her when they were last together. He said that tensions had been building up. He was feeling stressed about Stacey’s illness and around her relatives, particularly at the point when he could see that she was again beginning to deteriorate. She had miscarried very early in her pregnancy, and had begun to lose all hope. He confessed to losing his temper when her family were there, and handling her roughly. He had called the police during one of these heated arguments with her family. The police interviewed him subsequently, and Brianna had been taken to her parent’s place. He was ashamed and very sorry. He realised after this incident that he needed help with his anger, and promised to actively pursue counselling when he relocated. He was planning to return to his homeland to care for his ageing mother.

I went to see Stacey that same afternoon after a nap. The nurse on duty greeted me warmly – he remembered me from my own hospital admission. I asked to see Stacey. He told me to wait while he checked on her first. He came back soon afterwards and ushered me in to her room. Stacey’s father was outside the room, her mother was sitting against the wall at the foot of the bed. I came in and introduced myself. Her mother greeted me in a friendly manner; she asked me to call her by her first name. She withdrew considerately from the room, so that I could have a private word with Stacey.

I looked carefully at Stacey’s small skeletal figure propped up in the bed with pillows. Her head had dropped to one side; she was unconscious, frowning, and breathing heavily. There were two quite prominent lumps on her body above the blanket on areas not covered by her nightie; one was located on the right side of her chest, the other on the left side of her neck. Her (dark) hair had started to grow again. When she woke up, she indicated that I bring a chair close to her bedside. I then took her hand gently in mine, and while
stroking it lightly, smiled at her. It struck me suddenly how very much easier it was to be on my side of this dynamic.

Stacey could only utter a few words at a time. She said that she was “too sick”, and it would “not be long now”. She also said that she was not going to be able to hurt anyone anymore. I responded by saying that she had brought a lot of love and joy to Salvador’s life. She looked askance at me with her misty eyes. Yes, I said, I knew that to be true, because he had told me so. Stacey said that she had told Salvador to let her go; he was young, he would find someone else. I nodded slowly, I knew then that Stacey had decided to move on. I realised sadly that she now had little to live for; life would be extremely difficult, at least in the short term, and she did not appear to have the loving support and understanding she needed to come through this ordeal. She seemed to be closing doors, preparing to die.

Brianna died on the following Sunday morning. She had asked to be taken to her own home, but was unable to manage without intensive care. She was then taken back to the local hospital, where she died soon afterwards. I heard subsequently that there had been a small memorial service held at her grave site; attendance was restricted to a just a few family members. Caroline also died. Her children had urged her to undertake chemotherapy, because they believed it was her only hope.
Cancer (Mis)information
Cancer (Mis)information

In my neighbourhood there is a small, organised and well-trained group of locals, who support people receiving palliative care in their homes. The last time I saw this group together was some time ago, when they invited me to talk to them about my experience of critical illness. Members of this group visited me when I was very ill; they also provided Michael with (much needed) respite care. One of them, Hannah, has since become a friend.

Just a few weeks ago, Hannah invited me to accompany her to an information morning that was hosted by the palliative care support group. She said that a representative from a cancer lobby group was giving a free public presentation on cancer and the prevention of cancer. My immediate reaction to Hannah’s invitation was negative. I was familiar with this lobby group’s perspective and found it dogmatic and strongly biased. Nevertheless, Hannah persuaded me to go.

The presentation itself was well delivered, but I became increasingly irritated by the inaccuracy of the information being presented. There were at least two others in the room, who shared my disquiet with the quality of the material. Those who dared to, spoke up – myself included. Still, our questions and objections were not addressed satisfactorily. It soon became apparent that any further debate was futile.

I arrived back home feeling frustrated, and Michael suggested that I express my feelings in writing. He further suggested that I send a letter with my feedback of the information session to the lobby group’s head office in Sydney. Michael’s suggestion appealed to me. This represented an opportunity not only for emotional catharsis, but also for speaking on behalf of cancer sufferers themselves. This organisation could make a difference to the treatments cancer sufferers receive, and to the attitude of those with whom they interact. I
remembered, vividly, how unskilfully Brianna and Caroline had been treated by those closest to them, and how isolated emotionally they had become during their dying – a time when they most needed help and support.

The following is a copy of the letter I then wrote (names withheld):

To Whom It May Concern:

I have just attended a cancer information morning hosted by a group that provides palliative care support for local residents. The presentation was given by (one of your organisation’s representatives). This letter is my response to this presentation.

I will begin with some personal details so as to provide a context, from which this critique is given. In academic terms, I am a PhD candidate with the School of Health and Human Sciences at Southern Cross University, Lismore – in the Northern Rivers district. I am currently writing a PhD thesis on the experience of dying (from cancer). I have a Bachelor of Arts degree in Behavioural Studies (1989), and a Master of Arts degree in Art Therapy (1999). Professionally, I have worked for a number of years as a counsellor, consultant, and family therapist with individuals on an outreach basis and within agency settings. I have facilitated therapeutic group programs and co-ordinated the therapeutic group work activities of a large organisation. I have also worked extensively as a counsellor and support worker in a voluntary community service capacity in a variety of areas, including hospice support work.

In addition to this, I have significant experience of cancer. Six of my immediate family members have been diagnosed with cancer from which two of my sisters have died. I have personally suffered Stage IV cancer, including widespread metastatic bone cancer – the result of late stage breast disease. I have, for many years, dealt with members of the
medical profession and with complementary and alternative therapists.

This morning’s presentation was professional in the way it was delivered, so the issues I raise here are not about the presenter. My concern is that the findings of the research that I am doing for my PhD are at variance with the information presented. Please consider the following observations:

- Treatment recommendations were quoted to be “evidence-based”, and I know from personal experience and from my literature review that although the treatments recommended for cancer may be “best practice” treatments, they are not necessarily evidence-based. “Best practice” merely indicates that a particular treatment has frequently been used for a particular condition, not that the treatment is being recommended based on evidence that it is the most effective option available.

- The important role of complementary and alternative therapies is not accurately presented in (your organisation’s) literature nor, consequently, in the information session this morning. While it is true that Biomedicine is effective in detecting and treating some forms of cancer, it is equally true that some other forms of cancers do not respond to medical treatment. Some forms of cancer are considered untreatable and medically incurable. And yet, people do survive them. Biomedicine is not a holistic approach; it is one of many strategies available to cancer sufferers. (The information you are disseminating) seems to be treating Biomedicine as the only realistic treatment option for all cancers. This is ethically unsound.

- Mention was made of the placebo effect. The placebo effect has been found to work in the opposite direction. It is called the nocebo response – “I shall harm” (Walter
Kennedy, 1961). If the expectation is expressed that a person is not going to heal, that can equally prove to be a self-fulfilling prophecy.

- When biomedical practitioners find they cannot cure or treat a particular form of cancer, they often respond by giving what amounts to a death sentence. A more truthful response would be for practitioners to openly declare that Biomedicine is not holistic and does not have all the answers, and that while Biomedicine may not at this stage be able to treat a particular form of cancer, hope may lie elsewhere – because some cancer sufferers do survive the most aggressive and medically untreatable forms of cancer.

- I am not suggesting that a person should be given false hope. I do strongly advocate that all hope is not taken away. Cancer sufferers must be given wide ranging information that will provide them with an opportunity to look into other perhaps less conventional treatments, that may well provide help, even cure.

- Individuals must be allowed to take personal responsibility for their treatment. They must be allowed to choose the best treatment options. The best decisions are made when all options are communicated, and made available. This means that options other than medical treatments alone should be investigated and made known.

- More information on the environmental and lifestyle factors that cause cancer, xenoestrogens, and on breast cancer specifically is needed because it is the leading cause of death in women, particularly in the 45-64 year old age group (www.breastcancerfund.org).

- I know from my research that many clinical trials related to treatments for cancer are funded by pharmaceutical companies. Pharmaceutical biotechnology is a multi-
billion dollar industry world-wide. There is a vested interest in pharmaceutical companies to find (only) drug-related treatments for cancer.

- A question was asked during this morning’s information session about the type of trials being funded by (your organisation). Trials funded by drug companies are essentially biased. The concern is that (your organisation) may be reflecting this bias. I emphasise the fact – there are other effective approaches that should be examined without bias.

I suggest, for instance, that a research project might be conducted on those who have survived medically incurable forms of cancer. Their personal qualities and the methods of treatment they chose should be examined. The results of such a project could inspire hope and give direction to the many people whose cancers cannot be medically treated and cured.

These are just a few of the comments I feel compelled to make after listening to the information session this morning. Cancer is the leading underlying cause of death in Australia today, and the incidence of cancer is rising (ABS, 2006). The quality and accuracy of information on cancer is vitally important to everyone. The most beneficial outcome is that suffering will be averted, or at least ameliorated. For individuals who are facing the horrific and agonising experience of cancer, treatment decisions must be based on (all) the best information available. Treatment decisions make the difference between life and death, also between the quality of life and the quality of death.

Thank you for your attention,

Carmen Zammit B.A. (Behavioural Studies), M.A. (Art Therapy)

30th October 2006
Since writing this letter, I received an acknowledgement of receipt of my letter, with an assurance of a fuller response after their representative was consulted. However, the promised response never came.

How should I interpret this failure to reply? This was an organisation, which relies on financial support from the Government and from the general public, it is one, which I believe must, therefore, take responsibility and account for its actions. I had a reasonable expectation that I would receive a response characteristic of or befitting the profession which this organisation represents. The latest report shows that many of the Board Members are primarily from the medical profession. Considering the lives at stake, the extreme suffering involved, and the financial and emotional cost to the community, the response to cancer should be a thorough and concerted one. I, for one, would like to see responses to cancer, that are patient-centred and free from self-interest, bias and deception.
Withdrawing / Emerging
Withdrawing / Emerging

This portrait depicts my state of health at the time of this writing. It is now four and a half years after my initial diagnosis of metastatic cancer, and approximately two and a half years since my admission into the hospice I was not expected to leave. This image reflects my present state of being. Amazingly, I am alert and well. I have regained my health and mobility. I have taken myself off all the medication I was prescribed – a process that had taken courage and faith, and two years altogether to complete. The withdrawal process began when I first intuited that I was recovering. Until that time, I was reliant totally on my medication, which gave me a significant measure of pain relief and control of other symptoms.

When I was in the hospice and for some months afterwards, I was confined mostly to my bed, on which I lay quite still. My wanting to return home from the hospice was seen as an opportunity to grant my last request. I was told by my doctor in response to my inquiries that I could expect that my levels of medication would continue to increase until my death. However, contrary to all expectations, I very gradually became able to sit up independently, and then for increasingly longer periods of time. On discovering this hint of improvement in my health, I decided to begin to withdraw my medications, initially from the anxiety and sleeping tablets, then incrementally all the others. At that time, the medications I was taking included: morphine tablets (MS Contin for pain), a morphine liquid mixture (Ordine for “breakthrough” pain), paracetamol (Panamax for pain), docusate sodium and senna (Coloxyl with Senna laxative), Macrogol 3350 (Movicol sachet laxatives), metoclopramide tablets (Pramin for nausea), omeprazole (Lozec Acimax to reduce acid secretion in the stomach), Temazepam (to assist with sleep), Diazepam (to assist with anxiety), chlorpromazine (Largactyl, a major tranquilliser and neuroplegic), a selective serotonin reuptake inhibitor (Celepram anti-depressant) and a
bisphosphonate (zoledronic acid, Zometa). I withdrew from the minor drugs as soon as I felt I could, and I withdrew from the major drugs one at a time.

For example, I withdrew from 100 milligrams of morphine, morning and night, at an average rate of 10 milligrams per month. On two occasions, I needed to go back on to my previous dosage. On reflection, these were times of added stress. I became aware gradually of the fact that environmentally induced stress had a profoundly negative effect on me. I believe that this was because I was already dealing with an enormous amount of distress from being critically ill. Even those situations that were anticipated as pleasurable were sometimes experienced as stressful, as for example, when family or friends stayed over. My daily need for peace and quiet had become extremely important to me, and major disruptions to my routine affected me negatively. Over time, I learned to become aware of my physical and emotional needs and limitations, and to avoid or minimise any form of stress. When I perceived any physical or emotional distress, I would then wait until I had regained peace of mind and body, before continuing with my withdrawal process.

In terms of the morphine, I had the advantage of knowing that withdrawing from opiates is a physically painful process. I had worked as a drug addiction counsellor for some years and I had learned this from my heroin-dependent clients. When I consequently felt the pain of withdrawal, I knew it was to be expected. The challenge for me was to discern whether it was, in fact, the pain from malignant tumours. I judged this by noting the location of the pain. I reasoned that if it was tumour pain, it would be felt in those places I knew the tumours to be, especially the largest of them. I found this not to be the case, and so I felt the confidence to proceed.

It took about a year to withdraw totally from the morphine, then I began withdrawing from the anti-depressant, and so on, until I finally discontinued the last drug, Zometa, which was administered intravenously on a monthly
basis. In medical terms, Zometa is a bisphosphonate, an anti-resorptive agent used in the treatment of metabolic bone diseases – such as in my case, tumour-associated hypercalcaemia. My understanding of this terminology is that this drug stops the tumours from leaching calcium from the bones into the bloodstream (which is a toxic condition, fatal if left unattended); this drug also stops the bones from regenerating, and thus inhibits the further growth of malignant tumours in the bone. Like morphine, the bisphosphonate was not curative, it was only palliative. My withdrawal from the drugs in general was a slow and gradual process. The outcome – unknown to me at the start – was to be my total and successful withdrawal from all the medication.

The withdrawal process was a self-managed process, guided largely by my intuition. This was not the first time I had acted on insights about my health, and I had learned from painful experience not to ignore them. For me, following my intuition about my health was about obeying messages from my body. I had the distinct impression that I was getting better, in spite of my medical prognosis. When I first felt the inclination to withdraw from the medication, I encountered opposition from my doctors and nurses. I remember their expressions of surprise and puzzlement when I made decisions that did not conform to what they believed was true about my state of health. I was actually accused of being “in denial” by those people, who were convinced that I was doomed. I sensed that they truly believed in my “terminal” status, the hopelessness of my condition, and the efficacy of the drugs I was taking. Nevertheless, I was determined to proceed.

I acknowledge that the drugs were effective, but they also had dreadful side-effects. Some of the medications, like the morphine and the bisphosphonate (Zometa), had side-effects, which were ultimately fatal at the doses I was prescribed them. I was aware from the knowledge that I had gained from witnessing my two sisters’ deaths and from doing my own research, that death from morphine would mean a sure decline that ended with asphyxiation; and that death from the bisphosphonate would be preceded by multiple bone
fractures and/or necrosis of the jaw, with all the horrors of the disfiguring and often unsuccessful surgery that would result. It was difficult, perhaps impossible, to convey the reality of my terrible dilemma (death from malignant tumours or death from medical treatments) to people, medical or otherwise, who had not had the lived experience. This was a hellish time, one of interminable suffering; yet there eventually came an unexpected development, a solution to my dilemma. Though it may have seemed absurd to others at the time, I felt a distinct possibility that my health was improving.

In this self-portrait, I chose instinctively a light, bright coloured paper, on which to render the image, as opposed to the black paper, on which I rendered images of the dark and traumatic times of the past. This conveys the contrast between my state of being at the present time and that of past times in the hospice and for many months afterwards. In this illustration, the light colour of the paper comes through in the face. This suggests that the light is not merely surrounding me and thus produced strictly from an outside source. It emanates from within, reflecting a lightness of spirit, not previously felt.

**Summary**

This chapter described my RTA, which I realised was characterised by a trajectory of events, documented chronologically, to capture the detail of my life journey, in relation to my cancer diagnosis. This chapter provided a sequence of events, described my reflections on these events, and presented my artworks and my reflections on creating and interpreting these images and stories.

The images and stories portraying my life journey with cancer included works entitled: Origins, My Family, My Culture, Rag Doll, The Demon Within, The Silent Scream, The Fighter, Feather Inscape, Slipping Away, Living Horror, Mother, My Mother, Myself, Morphine, Heart of Peace, Living in the Shadows,
Cancer (Mis)information, and Withdrawing / Emerging. Accompanying reflections provided insights into the creation of the images and how I have come to interpret them and make sense of my experience of dying.

The aim of this thesis was primarily to describe my experience of dying. A second consideration was to describe the impact on family, friends and others. My initial objective was to write down my experiences in response to the many questions and concerns raised by family members and friends. I believed they were interested in making more informed decisions about their lives and treatments should they themselves be diagnosed with a life-threatening illness. Their behaviour, questions and emotional responses, suggested that they were interested in what actually happens during the dying process, so that they themselves could be somewhat prepared for the eventuality. I wanted to give a true account and accurate information, which in the first instance might help my own genetic family. Beyond this, I hoped to reach those interested parties, who would benefit from this information and knowledge, particularly those who themselves were diagnosed with a life-threatening illness, and those at risk of doing so. My hope was that it would also help their partners and carers, both personal and professional, to also know and understand the experience, so that they could give the support that comes from knowledge and empathy.

This RTA fulfils most or all of these aims and objectives, some of which can only be realised over time, as people resonate with my work and personal insights into what it is to experience dying, as an immediate and ever present reality.
Appendix A: Informed Consent

Information Sheet

**Title:** “The Experience of Dying: A Reflective Topical Autobiography”

I am undertaking a research project for my PhD, a thesis on the experience of dying. This is an autobiographical account, reflecting on the time in my life when I was critically ill and close to death. The aim of this research is primarily to describe the experience. My intention is to give a true account and accurate information, which in the first instance might be of assistance to my own genetic family, who have a pre-disposition to cancer. Beyond this, I hope to reach those interested parties, who would benefit from this information and knowledge; particularly those who themselves were diagnosed with a life-threatening illness and for whom cure is no longer the expected outcome. My hope is that this thesis will also help their partners and carers, both personal and professional, to gain a deeper understanding of the experience of dying so that they can give the support that comes from knowledge and empathy. This research is being conducted to meet the requirements for a PhD. I am working under the supervision of Professor Beverley Taylor RN RM PhD, Professor of Nursing, within the School of Health and Human Sciences, Southern Cross University.

As part of the formal requirements, you are being asked for your informed consent to participate in this study. Participation in this autobiography involves your agreement that my recollection of your part in my life story is accurate. A final write-up of the part of the thesis in which you are involved will be made available to you, to give you the opportunity to make changes related to its accuracy and to elaborate on information that may have been omitted or that may need clarification. The results of this research may be published in academic journals or presented at academic conferences.

Participating in this research is voluntary, and your confidentiality is assured. By way of protecting the participants’ identity, their role or relation in my story (for example, “sister”, “doctor”) will generally be used instead of names. Neither your name nor identifying information will be disclosed or published, except with your permission. You are free to withdraw your consent to further involvement at any time, without prejudice. A list of available counselling and support services is provided at the end of this form should you experience emotional upset, however this type of risk is not envisaged.
If you have any questions about your participation in this study, please contact the researcher, Carmen Zammit: phone (02) 6632 2518, email: czammi10@scu.edu.au
My supervisor, Professor Beverley Taylor, is also available to answer any queries: phone (02) 6620 3156, email: btaylor1@scu.edu.au

Signature of Researcher .......................................................... Date:

The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee (HREC). The Approval Number is ...........................................
If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the HREC through the Ethics Complaints Officer, Ms Suze Kelly, telephone (02) 6626 9139, 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.

Appendix A (cont.): Informed Consent
Informed Consent

Informed consent to participate in a Research Project

Title: “The Experience of Dying: A Reflective Topical Autobiography”

Researcher: Carmen Zammit

Researcher contact: phone: (02) 6632 2518,
email: czammi10@scu.edu.au

Participant: I agree to participate in the above research project. I have read and understand the details contained in the Information Sheet. I understand that neither my name nor identifying information will be disclosed or published, except with my permission. I have had the opportunity to ask questions about this study and I am satisfied with the answers received. I understand that I will be given a copy of this form to keep.

Name of Participant: ……………………………………………………………...

Signature of Participant: ……………………………………………………………..

Date: ……………………………………………………………..

I appreciate your willingness to participate in this research project. Please return this form as soon as possible in the envelope supplied.

The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee (HREC). The Approval Number is ……………………..
If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the HREC through the Ethics Complaints Officer, Ms Suze Kelly, telephone (02) 6626 9139, 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.

Appendix B: CISS “Cancer & Hope: Paths to Recovery” Seminar

“The Healing Self” – a presentation by Carmen Zammit
Pause, look at everyone, with soft eyes, a relaxed friendly countenance. Slowly, with pauses, ...

I’ve begun with that chant because it gives the different names of the Goddess, and brings to mind the different qualities associated with the feminine, but which exist in both men and women inclusively – qualities like Unconditional love, Nurturance, Deep knowing, Intuition, Inner guidance, Emotion – those qualities that tend to be devalued in our society, or are the cause of punishment and ridicule.

My journey has taught me not just to acknowledge and reclaim these qualities, but also to honour them. In this sense it’s about the sacred feminine – which is very much missing in our culture today. They were important in my journey – of healing my life, of healing myself.

I will begin my talk with a quote from Socrates: ‘The unexamined life is not worth living’.

In the last three years I have come to understand the profound wisdom of that statement. By examining my life, I was able to save my life. Today, I’d like to take you through that journey, the journey of how I survived so-called “terminal” cancer.

The information I share with you comes from two sources. Firstly, from the insights I gained from my lived experience of surviving cancer, and secondly, from the research that I am currently doing on cancer and survival for my PhD at Southern Cross University in Lismore.

My talk will be divided into three sections. The first section will be my testimonial. The second section will be a definition of terms. In the third section, I’ll take you through the journey I took, using my artwork to bring it to life. (Questions)
Appendix B (cont.): CISS “Cancer & Hope: Paths to Recovery” Seminar

(first section) Firstly, I’ll begin with my testimonial.

Three and a half years ago I was in St Vincent’s hospice with late stage breast cancer that had spread widely into the bones and tissues. My condition was considered terminal and death was imminent. I received palliative care, which included some 15 or so medications – mainly to manage the pain. There was no medical cure.

Today I live a normal life, free of medication. And in some ways I am in a better state now than before my illness.

(second section) Before talking about how this transformation happened, I’ll move on to the second section: my definition of the terms “Cancer & Hope: Paths to Recovery”.

“Cancer” is a word that I use with reservation. The word comes from a particular school of thought which describes the physical manifestation of disease. It therefore describes only one aspect of an illness. Here is another way of looking at illness. This was written by D.H. Lawrence, it’s from a poem called “Healing”:

I am not a mechanism, an assembly of various sections.
And it is not because the mechanism is working wrongly that I am ill.
I am ill because of wounds to the soul, to the deep emotional self…

“Hope” is about a desired outcome, an imagined future. In that sense it’s future oriented. Hope has a very important place. In fact, one of the characteristics of people who have experienced a remarkable recovery from disease is that they believe in the capacity for healing to occur.

But wishful thinking alone is not enough. We have to work towards our healing. It’s like people who smoke 60 cigarettes a day and are finally diagnosed with lung cancer. No amount of surgery, no amount of chemotherapy, and no amount of
radiotherapy will have a lasting effect unless they are willing to face their inner demons – those forces within themselves that are causing them to self-destruct. We must actively participate in – and in fact take charge of – our own recovery.

Appendix B (cont.): CISS “Cancer & Hope: Paths to Recovery” Seminar

There is in our society a tendency to take people’s hope away, to give what amounts to a time limit, a death sentence. I remember a doctor who thought he was doing the right thing when he said to me “I will tell you the truth. Your condition is terminal.” To me, it was like pointing the bone. The problem is that if you believe that message, it could cost you your life.

I am not suggesting that people should be given false hope – which I have found to mean giving inaccurate information that is designed to gain compliance with a treatment. I am strongly advocating that all hope is not taken away.

There is another aspect of hope I want to talk to you about: the shadow aspect of hope. What is the shadow aspect of hope?
The answer is: if hope is future-oriented, the shadow aspect is the present moment. It is the awfulness and horror, the present-time reality of having advanced cancer.

The paradox is that my “healing journey” began at that time, three and a half years ago in St Vincent’s hospice, when there seemed to be no hope, no future ahead of me.

So, my “Path to Recovery” began at that place when I felt absolutely and utterly alone, when there was nothing and no-one who could really help. I realised then that I had to help myself.

Here’s a poem that speaks to this realisation. It was written by one of our great contemporary poets, Mary Oliver. It is called “The Journey”.

One day you finally knew
what you had to do, and began,
though the voices around you
kept shouting
their bad advice –
though the whole house
began to tremble
and you felt the old tug
at your ankles.
“Mend my life!”
each voice cried.

Appendix B (cont.) : CISS “Cancer & Hope: Paths to Recovery” Seminar

But you didn’t stop.
You knew what you had to do,
though the wind pried
with its stiff fingers
at the very foundations,
though their melancholy
was terrible.
It was already late
enough, and a wild night,
and the road full of fallen
branches and stones.
But little by little,
as you left their voices behind,
the stars began to burn
through the sheets of clouds,
and there was a new voice
which you slowly
recognised as your own,
that kept you company
as you strove deeper and deeper
into the world,
determined to do
the only thing you could do –
determined to save
the only life you could save.

To me, this poem speaks to our desire to be rescued, to that part of us which is looking for a saviour – a person, a treatment or a drug that will save us. The poet Mary Oliver had a difficult childhood, but somehow through that she learned an incredible faith in herself. Her poem is about self-determination, about learning to have faith in yourself. It conveys the process of leaving all that is known behind, and in the process of doing that, though death and darkness may surround you, you discover that you begin to see in the dark – you find your own voice, you find your own way.

Appendix B (cont.): CISS “Cancer & Hope: Paths to Recovery” Seminar

**third section** my artwork (show image with each explanation)

**Origins** : The answer to the question of how this illness happened to me became clear with this first image. This collage was first created to express my response to the violence within the home. It came as quite a shock to realise that what started as my emotional and psychological state had eventually become my physical state.

**My family, my culture** : This illustration expresses how I saw my place within my family and co-incidentally within my culture – including my perception of the medical profession. It shows my sense of vulnerability, of fending off attacks. These postures were taken from family therapist Virginia Satir’s “Communication Stances”. Mine is the Placating Stance, which is essentially the victim role. I knew there was something wrong, but felt powerless to change it.

**Rag doll** : Again, this is an image of powerlessness. Compared to a china doll, this doll is treated less gently - it gets dragged by the hair and pulled around. This is an image of the perceived self.
The demon within: These two drawings are based on a healing dream about facing my inner demons. The insight I gained was that the demon (the damaging parent or authority figure) is not almighty after all. Here the demon turns out to be a mendicant who is respectfully asking, begging my forgiveness.

The silent scream: conveys my sense that people could not hear my inner scream when I was critically ill with cancer. And even if they did, there was nothing they could do. I was alone and in despair, and there was no-one and nothing that could help.

The fighter: When I was on high levels of morphine, my nights were filled with apocalyptic dreams and nightmares – of being punched, stabbed, caught in volcano eruptions, tsunamis and such. This was a dream figure, a man intent on knocking me out. In retrospect, this represents the aggressiveness of the cancer, and my feeling overwhelmed by it.

Feather inscape: expresses my longing for an escape – a place of beauty and peace. I subsequently noticed that this drawing contains images of the four elements – earth, water, air and fire – which enhance the feeling of harmony this landscape conveys to me. This image is also reminiscent of my birthplace, Malta.

Slipping away: was based on a dream featuring two of my sisters and I as children. I was the twelfth of thirteen children in my family, and six of my immediate family members had been diagnosed with cancer – my mother, myself, and four of my sisters (two of these sisters have died). At the time of this dream, I felt I was literally slipping away. This expresses my terror of losing my grip, as a fall would have meant sure death.

Living horror: This was not a dream, this drawing expresses the reality of my predicament when I had advanced cancer. The rope around my body and neck expresses my actual inability to move (because of the pain), the red spots represent widespread cancerous tumours, and the gun at my head which is aimed to kill conveys (like Russian Roulette) that death was imminent.
Mother: This was a turning point in my journey. At times, at the end of a series of nightmares this image of my mother would come. To me, this is an image of unconditional love. I noticed the effect this image had on me, the sense of comfort and healing I felt as a result. So much so, that I realised that I had to look upon myself in the way my mother had looked at me – with such warmth, such respect, and such love.

Heart of peace: (music!!) This is an image, which represents meditation and contemplation. I learned that instead of fighting and rejecting the cancer, I had to cooperate with the messages from my body and respond appropriately – with love – to my injuries, my tumours. This drawing depicts my radiating love from my heart to the tumours, to myself. A heart of peace in the eye of the storm.

Morphine: Though I was changing my internal reality, this was the actual physical state I was in. It was when I was in this state of heavy sedation and physical agony that my healing journey actually began. (story of private hospital?)

Withdrawing / emerging: represents my present state of well-being, one I have enjoyed since completing the process of withdrawing from all my medication just over a year ago. This self-portrait is drawn on light coloured paper, which is seen coming through in the image. This indicates that light is not merely coming from an outside source; it comes also from within – reflecting a lightness of being not previously felt.

People often say that cancer is a gift. There is no value at all in unrelenting suffering. The gift is that the experience of cancer has caused a change in me that nothing else has been able to.

In summary, this was a journey from victimhood or innocence, to self-empowerment and self-determination.
To recap, my path to recovery was in taking an inner journey at a time I was surely going to die. Through taking that journey, the pathway towards healing revealed itself. It began with inquiring into my present life circumstances, and then reviewing my life to determine how I got into the state I was in. This introspection led to insights which inspired spiritual and emotional healing, and which finally – and quite unexpectedly – led to physical healing.

The poet David Whyte points out that this happens in the great fairy stories, there’s always a moment when the child who has been abandoned on the road, or who is lost in the forest, finally just gives up. In their grief they fall against something – a tree or a stone, or they think it’s a tree and it’s actually a bear – and they lean against it and they sob, and all their grief comes out, and in that moment of actually leaning against the world – of allowing the world to support them – then the tree or the bear or the stone would speak back and it would say “What’s the matter? And what do you need?”

The great teaching in those fairy stories and mythologies is that you must have that kind of faith in the world. The world (our life) is as Yeats said – a source of revelation, not a problem to be solved.

To conclude, the Western medical solutions of surgery, chemotherapy and radiotherapy seem to be presented as the only option available, the only way to go. We are given just one path, no real choice. In reality, there are other paths that will take you there, and will get you there much more safely. As Jesus, the Nazarene said, “Physician, heal thyself.” This shows that it’s possible.
THE HEALING SELF:
A REFLECTIVE TOPICAL AUTOBIOGRAPHY ON SURVIVING ‘TERMINAL’ CANCER

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The purpose of this research is to offer an alternative and/or a supplementary approach to mainstream cancer treatments.

Statistics reveal that cancer is the leading cause of death in Australia, particularly amongst women aged 25-64 and men aged 45-84 years. Research efforts, which endeavour to improve survival rates and to improve the quality of living or dying of people diagnosed with cancer, tend to exclude or de-emphasise the perspective of the individual, personal experience. Using Reflective Topical Autobiography as the research methodology, the author’s process of healing is described from the time of receiving palliative care three and half years ago for widely disseminated, late stage, ‘terminal’ cancer to the present time of living a normal life, free of medication.

The significance of this study is that the author’s experiences and insights may help others to understand how to create the conditions that will enable healing to take place, so that others may survive even late stage cancer and live well without the need for conventional cancer treatments. This presentation features the author’s artwork which vividly illustrates the inner journey taken towards healing – a process which unfolds as both life affirming and spiritually enriching.
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