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Coping with Breast Cancer:  
Women's Lived Experiences with Illness and  
Dying and the Role of Faith in Facilitating  
Well-Being.

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## Abstract.

This qualitative empirical study examines how women cope with breast cancer and whether faith plays a role in facilitating coping. How women achieve a sense of faith and optimism in their world and their surroundings, in the midst of pain and suffering, is also an area that is given due attention.

Can women find meaning in their experiences of a life-threatening disease? Can they believe that 'all will be well', even when they face an uncertain future? Such questions are raised at the beginning of this study and answered in the chapters that follow. Other themes such as 'identity', 'body image' and 'the nature of dying in an institution', are discussed in order to understand how they affect a person's struggle to come to terms with a disease such as cancer.

The intimate stories of twenty women with breast cancer were analysed in this thesis. Access to these women was obtained through three cancer- support groups. Written permission was obtained from the co-ordinators of these groups before the women were approached. Further, prior to interviewing the women, I carried out volunteer work in both a palliative care ward and a hospice, in order to gain an insight into the inner battles of cancer patients. My firsthand experience with dying people gave me a better understanding of the nature of dying, illness and, cancer itself. This was of great benefit to my study. My experience as a palliative volunteer worker is documented in chapter five.

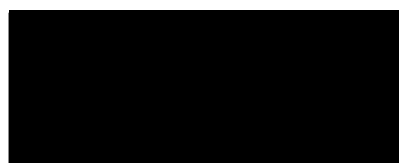
In-depth interviews were carried out in women's home. They were recorded and later coded. This thesis is rich in qualitative material. A substantial amount of what the women had to say about their personal experiences has been included in chapter seven. In my desire to remain faithful to what the women had to say about their journey with breast cancer, I have presented the narratives in their own words. At the end of each story I have included an analysis and a diagram that traces factors facilitating coping.

My findings indicate that over half of the women in this study relied upon faith as a means of attaining trust and confidence in their surroundings. The most powerful source that women relied upon as a tool for coping with illness was support groups. It was in these support groups that the women felt empowered in a number of ways.

Through these groups women received education about treatment and medical professionals; women also found that they could trust and rely on other women to understand their pain. 'Emotional support was, thus, an important outcome of attending support groups.

Other sources relied upon as a means of coping with breast cancer included alternative strategies such as meditation, tai chi, yoga and belief in oriental medicine. Family and friends and competent and compassionate medical practitioners and counsellors also provided the women with inspiration and encouragement to get through each day.

To the best of my knowledge, this thesis contains no material previously published or written by another person, except where due reference is made in the text of this thesis. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other institution.



Marcelle Cacciattolo

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I would like to thank Lyn Peters and Quintin Fernando for their editing skills. Marnie Neal has also been a great friend throughout the years. I have enjoyed our conversations and her positive outlook to the completion of my work.

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## **Chapter One: Living With Breast Cancer.**

### **Incidence of Breast Cancer.**

Breast cancer affects many women from varying cultural and economic backgrounds. It is the cause of a great deal of misery and despair amongst those individuals afflicted with this tragedy. The cause of breast cancer is something still unknown to scientists. Consequently, there is no cure for this disease at present. Breast cancer is the most common form of cancer amongst Victorian women. In 1996, the Anti-Cancer Council of Victoria published the following facts and figures with regard to the amount of Victorian women diagnosed with breast cancer:

- One in fifteen Australian women will develop breast cancer during their lives.
- In Victoria about 1,800 women are diagnosed each year, making it the most common form of cancer in Victorian women.
- In 1993, breast cancer was diagnosed in 2,173 women. Half of these women were aged over 60 years.
- In the same year, breast cancer caused the deaths of 731 women. There were 73 new cases per 100,000 for women. Further, the rate of new cancers in women is increasing, largely due to increased detection with mammography.
- The life-time risks of developing this cancer were 1 in 12 for women.
- The death rates were 21 per 100,000 women. Death rates have remained constant since 1982.

*Victorian facts and figures are supplied from the Anti-Cancer Council of Victoria Epidemiology Centre, 1996.*

These figures above indicate that breast cancer is a serious problem for Australian women. Although there has been tremendous progress in the diagnosis, treatment and management of breast cancer in the last decade, the social implications for women with this disease remains uncertain. Unquestionably, breast cancer brings with it certain changes in an individual's lifestyle. Assumptions based on life and death are seriously challenged. Previously held notions linked to identity, body image, health and sickness are scrutinised when chronic illness strikes; lifestyles

alter and perceptions tied to 'self' change when a person is faced with a body that is diseased and has broken down.

Considering the high rate of breast cancer diagnosed each year, it is imperative that insight is shed into the various ways women cope with and adapt to life changes when cancer strikes. Examining social environments and the level of support received from family, friends and medical practitioners is essential if understanding is to be gained into how women rebuild their lives. Aydin and Reardon (1993:265) argue,

The choice of coping strategy influences the extent to which cancer patients engage in behaviours that are considered health enhancing. To the extent that cancer patients engage in coping strategies that accommodate change, they are more likely to make healthful changes in their lifestyles.

How women in this study attain a level of well-being that enhances a positive outlook to life, is a focal point of this thesis. Identifying the various patterns and skills adopted by these women in coping with breast cancer is an area that is given much consideration to in the chapters that follow.

It is crucial to understand and address the concept of coping if we are to dispel destructive myths and stereotypes linked to the affliction of cancer. Often cancer can be viewed as a stigma that seeks to cause havoc upon the life of its victim (Herzlich and Pierret 1984). Kolb (1975) states that individuals who have been disfigured or deformed in any way will often be treated negatively by society. A diagnosis of breast cancer can bring with it operations, chemotherapy, surgical scars and loss of hair. During the impact phase of a diagnosis of breast cancer, feelings of disorientation, fear, helplessness and loneliness overwhelm the individual (Johnson and Spilka 1991; Roakach 2000). Further, situational factors such as the site of cancer, the stage of disease, whether one is in treatment and the time since first being diagnosed, are additional influences as to how cancer patients perceive their illness

(Dunkel-Schetter *et al.* 1992). It is known that breast cancer produces a variety of adjustment problems including depression (Brown 1978; Jones *et al.* 1990), anger or hostility (Mickley and Soeken 1993), helplessness (Brandt 1987) and feelings of shame and worthlessness (Kagawa-Sinager 1987; Schover 1991).

When women are forced to undergo changes in their physical appearance, body image can be severely tarnished. Mastectomy surgery for example can result in feelings of inadequacy, vulnerability and weakness (Boughton 2000). Potter and Ship (2001:309) claim, 'at least 80 percent of survivors of breast cancer report some psychological distress, including problems with body image and self-image, sexual problems, and effects on relationships, priorities and goals for the future'. Considering the sexual significance of the breast in society, where attractiveness is often tied to the cup size of a woman's bra, women who do not fit the mould can feel ashamed of their bodies. The victim of breast cancer, who has only one breast, or whose breast is severely deformed as a result of surgery, can be made to feel humiliated and embarrassed about her exterior parts (Kantor and Houldin 1999). Overwhelming fears tied to disease and a dysfunctional attitude to living and dying can soon set in rendering the victim helpless in a sea of destructive emotions; women, unsure of their fate, will commonly encounter feelings such as anxiety, discomfort and existential uncertainty (Johnson and Spilka 1991). When faced with an illness that seeks to destroy healthy bodily tissue, an outlook to recovery can remain grim and bleak. Thus, how individuals choose to view their illness and the types of social pressures placed upon them will determine not only their quality of life, but also their ability to cope in a productive and meaningful way. Chapter three focuses on the notion of body image and breast cancer in greater detail. Here I attempt to examine the impact of breast cancer upon self-esteem, perceptions of self and sexuality. I also look at notions attached to body image and their influence upon a woman's ability to cope with illness.

When investigating how women cope with a diseased body it is also imperative to consider the role of social and cultural domains. Sociocultural factors and processes shape the detection and management of breast cancer. Culture plays a vital role in establishing frameworks that mould our perceptions of what a diseased body actually means. Gifford (1991:174) points out,

Experiences of cancer are culturally shaped and although it is impossible to know about all specific beliefs, we must recognise that differences exist. Cultural beliefs play an important role in whether people seek early diagnosis, how they understand their disease, the kind of support they are willing to accept, decisions about treatment and how they experience the process of getting well and dying.

Entwined within this cultural framework is an elaborate network of codes of conduct bent on defining perceptions of illness. The cultural mosaic of meaning through which we understand and make sense of our world also provides standards of behaving in the presence of disease. Shared concepts, rules and regulations that underline and are expressed in the way we live, will either assist or inhibit coping. Further, understanding the inter-play between themes such as coping strategies and faith, coping strategies and body image, coping strategies and identity can highlight new and innovative ways of approaching and addressing illness. This thesis attempts to examine these themes with some depth in the latter chapters. Not only do I draw attention to the inter-connections between coping and certain cultural concepts, but I also inspect the role of identity in chapter four. Here my aim is to examine how identity is shaped by cultural influences and how this, in turn, may impact upon coping when cancer strikes

This thesis also examines the intersection of the following issues: women and religion, women and health, religion and health. Women were chosen as the focus of this study because one of my aims is to understand women's experiences from their own viewpoints. A vast amount of literature today is written by men, for men and fails

to consider what women have to say on issues such as politics, economics, religion, health and education. As King (1989:1) points out,

In the manifold web of social interrelations women have been central everywhere, but they have always stood at the intersection of patterns not made or shaped by them. Their role has been narrowly circumscribed by their biological function of producing children and by the associated tasks of nurturing and caring for the young as well as the sick, the old, the infirm. Women's activities have largely been relegated to the private sphere whereas the public domain, where history and culture are actively made and created, has predominantly been the world of men. Women have remained marginal and largely invisible in the public world and seldom, if ever, have their voices been heard.

In providing a forum whereby women are able to tell their own stories, in their own words, in their own time, a greater understanding of how women in this study respond to health, sickness, cancer, disease, body image, death and dying is achievable. Giving interviewees the opportunity to voice personal opinions of their experiences with cancer helps highlight what they essentially consider to be important in their battle with illness.

Examining what the women in this research have to say about spirituality and faith, as a means of dealing with chronic illness, is a central aim in this research. Feminists often criticise interpretations given to the religious dimensions of women's lives (Falk and Gross 1980; McFague 1983; Ruether 1972). They believe that great proportions of these experiences are set within the boundaries of a patriarchal system of feeling and thinking. Many feminist voices also disagree with religious ways of perceiving the world. They argue that men have been the sole contributors to such definitions,

Men have named things and people, men have thought, invented the world, they have mapped out reality for themselves and established sharply drawn boundaries within it. Women have been assigned their place and role within the scheme of things made by men alone. (King 1989:26)

Consequently, many feminists have sought to redefine traditional notions assigned to language, the world, religion, culture, values and attitudes. This has been done in a bid to create equal representations of community and faith, the experiences of men

and women, the acceptance of differences and the annihilation of the 'other'. Collins (1982:366) states,

Wholeness is based on a multi-dimensional vision of the world, rather than on a single vision which has dominated Western culture and most theological thought. Such a multi-dimensional vision means the ability to grasp complexity, to live with ambiguity, and to enjoy the great variety that exists in the world. Wholeness does not imply the eradication of differences, or the fear of a monotonous unisexual creature...On the contrary, wholeness of vision may lead to a multiplication of differences, as people are able to choose freely the person they want to be rather than following a pattern of one they are expected to be.

In order to grapple with the female religious experience and to define it more sharply, it is important to look at the religious lives and experiences of women. Women must be at the centre of any investigation that seeks to explore their own religious convictions and philosophies. Establishing a research design that is also open to the social pressures and cultural restraints that permeate the lives of women enables the exposure of hidden truths. Further, in providing an avenue whereby women can assert their own interpretations of spirituality, faith, health and sexuality, there can evolve a new level of consciousness and self-understanding. Analysing women's inner strengths and spiritual powers can, according to King (1989:87),

Open up decisive moments of revelation which point to transcendence and spiritual liberation...To share other women's experiences, struggles and thoughts is a catharsis, a cleansing and strengthening process whereby a woman can gain greater clarity of vision and become more transparent to herself.

Thus, women's present dealings with issues to do with life and death embody important experiences worthy of researching and documenting. Women today radiate a power and insight that is fundamentally rooted in their participation in the private and public sphere. Therefore, we must acknowledge that hidden deep within their rich experiences, embedded firmly within their personal and social lives, lies a rich spiritual heritage in need of exposure.

In understanding the various social and cultural factors that influence women's experiences with breast cancer, this introduction has been divided into a number of sections. Firstly, I investigate meanings attached to health, illness and culture. The intention here is to provide a framework for allowing us to think about how culture and social meanings shape concepts such as 'health', 'illness' and 'disease'. Secondly, I explore some of the strategies women with breast cancer use to come to terms with illness and disease. In doing so I make clear the extent to which breast cancer affects the social settings of its victims.

### **Meanings attached to health, illness and cancer.**

*The fact of 'health' is a cultural fact in the broadest sense of the term, which is to say at once political, economic and social. Which is to say that it's bound up with a certain state of individual and collective consciousness. Each period has its own notion of 'normality'. (Foucault 1983:175)*

*When a patient is severely ill, he is often treated like a person with no right to an opinion. It is often someone else who makes the decision if and when a patient should be hospitalised. It would take little to remember that the sick person too has feelings, has wishes, has opinions, and has — most important of all — the right to be heard. (Kubler-Ross 1997:22)*

The quotations above epitomise some of the contrasting views on health, illness and disease in Western society. Seemingly self-evident concepts such as 'health', 'ill health', 'diseased body' and 'sickness' are understood on the basis of societal values and cultural meanings given to them. Thus, being sick, or being healthy, is not simply a physical or biological state. Social contexts and images are placed on individual health experiences and medical practices. This means that human disease always reflects the outcome of the process of interaction between human biology and human social interaction, a process in which culture holds a vital position.

Representations of illness and disease through popular media and day-to-day conversations also add to the various ways in which the 'unhealthy body' is

perceived. Gifford (1991) makes the distinction between the concepts 'disease' and 'illness'. She defines disease as 'abnormalities in the structure and function of the body organs and systems' (p.172) and illness as 'experiences of disvalued changes in states of being and in social function' (*ibid.*). The distinction between these two notions is important because an individual may be plagued with disease but not suffer symptoms associated with illness (*ibid.*). In linking this to breast cancer, it is only when women decide to 'action' their disease, through treatment and therapy, that they are viewed as being ill. In the case of some diseases, victims may not have any side affects, and may feel perfectly healthy, as seen in the initial stages of skin cancer. Yet, their ignorance of their diseased bodies may unfortunately result in advanced illness later on.

Descriptions of ageing, illness and disease have received the attention of Western novelists, poets, and playwrights for centuries, especially leprosy, the plague, tuberculosis, cancer, syphilis and mental disorders (Horst and Daemmrich 1987:90). Terrors of physical decay, pain, suffering and death constitute the many scenes of fictional soaps and literary works as well as songs and folk stories; images attached to healthy and diseased bodies, are formed, circulated and passed on. Lupton (1994) believes that these forms of presenting knowledge to the general public manipulate and direct people's understandings of medicine, health care, disease and illness. She states, 'people construct their understandings of the world, including their beliefs about medicine and disease, from their interaction with cultural products as well as personal experiences and discussions with others' (p.17). When individuals have little or no direct experience of being sick and rely on objective states of reasoning in which to formulate their opinions, attitudes to illness and disease may be biased and misinformed. Thus, illness and health are social facts as well as biological facts — the various ways in which people respond to and cope with illness is reflective of their

environment and the collective ties which bind them to a prevalent mode of thinking and feeling.

Humans have at all times tried to understand illness. Depending upon the cultural thinking of time and place, people have ascribed to disease different meanings. In a study of cultural diseases Sontag (1978) contrasts contemporary social attitudes to cancer with attitudes to tuberculosis. According to her findings, in the mid 18<sup>th</sup> century, when romanticism flourished and the human soul was aligned with the elements of nature, tuberculosis was 'thought to come from' too much passion, afflicting the reckless and sensual' (p.21). Sontag claims that tuberculosis was linked to images of purity and innocence. Despite the victim's often harrowing experiences of pain and suffering at the hands of this disease, despite the sufferer's battle with fever, fatigue, night sweats, loss of appetite and the loss of weight, tuberculosis was seen as, 'a disease of time; it speeds life up, highlights it, spiritualizes it' (p.14). Tuberculosis was thus the killer of youth that plagued 'the more beautiful' (p.17).

In contrast, cancer, according to Sontag, is socially regarded as, 'ill-omened, abominable and repugnant to the senses' (p.9). Cancer, Sontag writes, 'can be a scandal that jeopardizes one's love life, one's chance of promotion, even one's job' (p.8). Cancer, unlike tuberculosis, is seen as 'de-sexualising' (p.13), afflicting those who are weak, repressed and angry (p.21). Further, cancer is a disease that is out of control, a disease that mutilates healthy body parts (p.15). In the case of breast cancer, many metaphors associated with this disease take the form of disfigured women who are unnatural and not whole. The dangers associated with metaphors that portray the body in a specific way is highlighted by McGuire (1996:108),

When the metaphorical meanings of body are culturally imposed by a dominant ideology, they have the potential to inflict on some persons (especially the relatively powerless such as minorities and women) a negative self-image, further distress, ill body and emotional experiences, and often outright abuse.

Many women who have endured mastectomies must therefore not only suffer with the prospect of a looming death, but are often made to feel incomplete in the eyes of the world. Social meanings and metaphors for illness can therefore cause great distress and anxiety for those individuals whose bodies have been tampered with. Metaphors can also be dangerous in that they take away the originality of a person's pain (McGuire 1996:108). When labels are placed on the sick, when stereotypical views of illness dominate the cultural circles of sufferers, coping can indeed become a painful task. It is therefore essential that women share their various coping experiences with each other and the outside world. Providing a window into the different ways women attempt to heal their diseased bodies will assist in shattering negative labels and dysfunctional social images.

Popular media and stereotypical views do not only dominate labels and representations given to health and illness. Scientific views on health, illness, disease and the body also govern public and private discourse. Physicians and health professionals have their own means and standards of defining, diagnosing, and treating medical problems — they seek to find answers to disease and illness from a specialised point of view. Subsequently, beliefs, theories and practices aligned with scientific rationales are almost always pre-governed and dominated by concepts, methods and principles of a biomedical nature (Mishler and AmaraSingham 1981:2).

The aims and standards of medical practice in their discoveries of cures, vaccines and newfound illnesses are also guided by social norms and cultural values — political and economic interests shape them. As Engel (1977:130) once noted, 'the dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables'. Thus, the complex relations of specific settings and institutions, the link between culture and environment to

social meanings of illness and health, are often neglected and cast aside. What has eventuated as a direct result of this is a biomedical model approach to understanding disease which is treated, 'as the representation or picture of reality rather than understood as a representation in itself' (Mishler and AmaraSingham 1981:1).

An increase in a biomedical approach to studying breast cancer often fails to take into account the lived emotional experiences of women. A full understanding of the effects of sickness on states of complete physical, mental and social well-being is ignored when illness is represented in a scientific way. When illness is objectified and the subjective realm becomes marginalized and side-tracked, emotions, feelings and thought-patterns are deemed trivial and unimportant. In the case of breast cancer, Langellier and Sullivan (1998:80) note,

As a separable body part, the medicalized breast is not signified with femininity and sexuality. Breast talk mutes the aesthetic, the functional, the maternal, the feminine, and the sexual meanings of breasts, and it de-emphasizes the uniqueness of breast cancer in distinction from other cancers. Breasts are constructed as physical body parts with disease but without addressing emotional issues of breasted experience in the context of women's bodies and lives. Talk of the medicalized breast views it from the outside rather than the inside, contributing to an alienated body image, and in terms of parts rather than the whole body in its social relations, contributing to a fragmented body image

The exclusive use of the biomedical model results in an approach that fails to explore disease from the social, cultural, and institutional contexts within which they occur. When research into breast cancer treats the breast as separate from the whole person, problems arise with regard to an accurate interpretation given to the experience of illness. This thesis is therefore aware of the restrictions placed on research when women are not given the opportunity to tell their stories. Chapter seven takes note of the variety of ways in which women in this study cope with breast cancer. The narratives of these women are relied upon in this section as a means of asserting the various ways a life threatening illness can be dealt with.

Often feelings and personal emotions encountered by victims of disease are deemed irrelevant in light of scientific reasoning. Nettleton (1995) points out that inherent in Western medicine is the assumption that truth lies in objective science based on empirical observation and induction. She claims that this biomedical view of health and illness is particularly limiting as it tells us nothing about how illness is experienced. Further, 'signs' and 'symptoms' become central to investigations into disease whereby, 'the body is isolated from the person, the social material causes of disease are neglected, and the subjective interpretations and meanings of health and illness are deemed irrelevant' (p.3). Thus, the individual patient becomes more or less a passive physical site for disease. Manifestation, and the disease itself, exists as a distinct entity whereby, 'rationalized biomedicine assumes a mind-body dualism, in which physical diseases and their causes are presumed to be located strictly within the body' (McGuire 1993:147). Inner thoughts and reflections, spirituality, faith and emotional ties are not attached to the infected body, for the body is seen as a machine that has malfunctioned and is in need of repair. The biomedical view thus strips away specific types of meaning given to illness and disease.

Social researchers need to systematically explore the various coping strategies adopted by women in their dealings with cancer. In openly discussing women's experiences with breast cancer and in focusing on representations of illness that are not bound by scientific ethics, scientists can draw attention to various ways of dealing with illness. Allowing women the freedom to discuss their methods of attaining courage in their battle with illness can further encourage other women to voice their own concerns and fears (Martin 1987). Research on breast cancer thus needs to examine the whole person rather than specific anatomical parts. In exposing women's internal voices to sickness, dying and recovery, there can evolve an insight into effective coping techniques. Radley (1994), in his research on explanations of health and illness in social life, reports that disease, illness and sickness cannot be

regarded as similar. He shows that by limiting ourselves to the biomedical model we fail to appreciate what illness means to individuals, to society and to health professionals. Further, he reminds readers that the way in which individuals make sense of their health will influence not only how they approach their illness, but also their response to researchers in the field. In understanding the impact of cancer on the lives of its victims, social and psychological models need to be implemented by researchers if a fuller understanding of this disease is to be obtained (Fife 1994).

When investigating such themes as disease and illness, McGuire (1996) asserts it essential that a holistic approach to illness is taken on board. Rather than simply concentrating on the symptoms of disease, attention must be given to the subjective state of thinking and feeling. Research carried out by the sociology of religion, that is tied to illness and disease, is seen by McGuire as failing in its attempt to look at the 'spirit' of individuals (p.102). According to McGuire, when examining the body, sociologists of religion tend to focus on 'the cognitive functions of the mind' (p.102). As a consequence of this the subjective state is seen to be unimportant; emotions and thoughts are silenced and experiences take on a rational and external framework. When examining how an illness such as breast cancer impacts upon women's lives, it is essential to listen to what women have to say at both the subjective and objective level. In McGuire's words,

In order to understand the role of religion in healing we must go deeper than believers' ideas, attitudes, norms — although these are not irrelevant. The experiences of suffering, pain and illness are not merely "in the body", or "in the mind or spirit"; rather they are experienced by the whole person as assaults on the body /mind/self. (1996:102)

Understanding that research tied to themes such as disease, the body, dying and illness should encompass both social and cultural domains alongside inner and outer states of reasoning, is imperative in this study.

### **Dealing with the crisis of breast cancer.**

Because normal life experiences often involve crisis-laden events most of us will undoubtedly have to face some kind of tragedy in our lives. Being human means that there are times when "everything is on the line", so to speak. It also means that there are times when we do not feel in control of our actions. When the lifestyles of people are threatened, a crisis is surely felt. This can be due to experiencing unforeseen events which bring great pain and distress to our lives. The death of a loved one, the sickness of a friend, the murder of an innocent child, are all events which arouse universal feelings of grief and sorrow in human lives. Facing such devastating circumstances can also threaten to destroy emotional and physical qualities of human existence such as integrity, honour and self-esteem. Thus, when the unexpected happens — when individuals are faced with an early death, when surgery or medical treatment fails, or produces even worse health, when infants or children die, when illness remains chronic and debilitating—existence can take on a whole new meaning.

Life takes on a whole new meaning in the case of breast cancer, whereby introduced feelings of helplessness and shock can create unstable lifestyles. Gabe *et al.* (1991:453) state that, 'the onset of chronic illness represents an assault not only on the person's physical self, but also on the person's sense of identity, calling into doubt the person's self worth'. In the presence of cancer, perceptions of 'self' and 'identity' are easily shattered where, 'loss of confidence in the body leads to loss of confidence in social interaction' (*ibid.*). This type of illness brings with it a certain fear about the future alongside an uncertainty of the past. A breast cancer patient's quality of life may also revolve around operations, chemotherapy, radiotherapy, weight loss and bouts of nausea. As one woman with breast cancer explains,

It was hell. The worst year of my life. I managed to keep working, just taking 5 days off each month. But it was not just how sick it left me feeling, but the other things with the body. I guess I do resent it in many ways, because of the

changes that took place, I think I am stuck with. With the premature menopause, the hot flushes, the loss of taste and smell and the hypersensitivity to some things. (Gawler 1994:27)

A diagnosis of cancer can therefore challenge every dimension of an individual's physical, emotional and spiritual make-up. If such dimensions are not given support and nurtured by social networks, if victims of illness are made to feel like outcasts because of stigmas attached to their biological state, then coping with sickness inevitably becomes an incredibly difficult task. In linking this to cancer patients, those unable to attain a sense of comfort from the distress of their condition are likely to become engulfed by feelings of guilt, suffering and fear (Wiklund *et al.* 1998). Cancer, in disrupting lifestyles and challenging the very values that make life worth living, forces victims to confront new experiences. Hence, victims of cancer are affected by their illness in many ways. Perceptions of their surrounding environment are altered, and sometimes damaged. In the process of battling with chronic illness, jobs are lost, never regained and new vocations in life are established. Families are split, or drawn closer together. Friendships are weakened, or are strengthened by the battle; outlooks to life falter, or rise to the struggle (Gotay 1985). Whichever the case, lives are never the same once cancer strikes.

There is an abundance of literature that suggests that personal adjustment to chronic illness such as breast cancer is dependant on the individual's ability to make sense of the threatening experience (Freund and McGuire 1991:147). The capacity to find personal meaning in suffering is important when battling illness. Confronting the misfortunes of existence and preserving the remnants of one's life although days may be numbered, allow victims to perceive their condition in a different light. The capacity to rise above a diagnosis of cancer is sustained when the purpose of suffering is linked to a concrete meaning in personal existence (Greenstein and Breitbart 2000). A person's sense of empowerment — a feeling that one can handle

stressful situations and still have a fulfilled life, is thus a key component in being able to successfully deal with tragedy.

Freund and McGuire (1991) examine the role of 'power' in a person's ability to get 'what one wants and to get things done' (p.7). Their theory is based on the premise that power is the driving force that motivates individuals to take action when ill, to deal with the uncertainties of sickness, to move forward in the road to recovery. According to Freund and McGuire the socialisation process influences the level of power a person feels he or she has. This can be seen when they write,

Much of our sense of self is developed during our socialisation in response to other people's attitudes and treatment of us. How we feel about ourselves depends very much on both the extent to which social interactions validate or affirm our sense of self and our social position. How competent and capable we feel to manage various stressors also contributes to our sense of self and health. (p.107)

Individuals who have been severely oppressed, demoralised, or subordinated, may find it increasingly difficult to cope with illness. Personal empowerment is essentially important to well-being and contributes to people's experiences of health and illness; in the presence of personal control, individuals are able to feel safe and secure in their social surroundings. Personal empowerment and faith is a theme that is given close consideration in the next chapter.

This thesis aims to question the role of faith in the lives of women who I interview. How faith helps these women to accept, cope and re-evaluate their illness is an important theme. In order to investigate such a topic it is important that the concept of faith is defined and clarified. Faith means different things to different people. There is not a universal definition for this word, which is shared by all members of society. Subsequently it is imperative that I define faith in my own terms. Such a definition will be undertaken in the next chapter alongside a clarification of the concept 'faith' within the context of this study.

## **Chapter Two: Sociological Approaches to Breast Cancer and Faith.**

### **Introduction.**

In chapter one I discussed the human problem of breast cancer and the need to understand in greater depth and clarity how women in this research cope with this disease. This chapter examines social and cultural factors affecting coping. I will discuss how social networks facilitate coping with breast cancer. The role of family and friends and the work of medical professionals in facilitating coping strategies are given some consideration. Secondly I will examine the role of religion in establishing coping mechanisms. Here I take note of the variety of ways in which religion can provide relief from suffering. Following this, the place of faith, spirituality and breast cancer in sociological research is developed in greater detail. As this thesis is concerned with women's faith and spirituality in coping, pinpointing previous research carried out in this field is essential. Definitions of key terms such as 'faith' and 'spirituality' are also included in this chapter.

### **The importance of Social Networks in Coping with Breast Cancer.**

In the past, social scientists, interested in understanding how breast cancer victims cope emotionally and mentally with their illness, have centred on the significance of social networks in providing comfort and stability to women afflicted with this disease.<sup>1</sup> Goldberg and Cullen's (1985) review indicates that the beneficial force of social supports in helping cancer patients adjust to the disease has been studied by many academics. Research into the impact of social networks in changing, or eliminating the primary sources of

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<sup>1</sup> A social network generally refers to an organisation of personal ties in which affect and/or instrumental aid is exchanged (Albrecht and Adelman 1984). As Gottlieb (1983:29) explains 'people are embedded in a social network composed of close associates who are important in the individual's affective life and who generate both support and stress at different times and in response to different life demands'. Social support then provides a foundation for both the physical, social and psychological aspects of illness.

threat to the individual faced with illness, pivot extensively on the following common themes: Family and friends (Ma 1996; Prury 1983; Zimmerman and Connor 1989), religion (Daaleman 2000; Ellison and Taylor 1996; Vanderpool and Levin 1990), work environment (Allen 2001; Pedro 2001) and professional and self help groups (Fobair 1997; Gore-Felton and Spiegel 1999; Hurdle 2001; Mok 2001).

Medical professionals such as doctors, social workers, pharmacists and nurses, our peers and those, with whom we live, shape our experiences and understandings of disease. Doctors for example affect actions taken in order to fight disease. Their ability to take control over prevention, treatment and prognosis of illness can influence attitudes to recovery (Major *et al.* 1997; Taylor *et al.* 1984). In the case of breast cancer, the type of information a practitioner gives to a patient, or the way in which medical professionals treat a patient, can largely influence a woman's experiences of illness (Nathan 1998). Kauffman (1987:67) notes,

Open and honest communication with health care professionals is vital to establishing a climate of trust and mutual respect, which can foster healing and renewal. Open communication allows both the patient and the physician to understand that they are working as equal team members on the very important project of beating back the progress of disease.

Women with breast cancer, who are confident when interacting with doctors, who feel supported and cared for by specialists, are likely to feel valued and respected. However, the social worker who intimidates patients or who appears unsympathetic to emotional and psychological needs, can promote feelings of vulnerability and helplessness. Hence, the type of care women receive from medical representatives can largely determine the way illness is perceived and dealt with. A caring nurse, or a sensitive doctor, can dispel painful notions of isolation and alienation. In saying this I refer to de Swaan's (1990:48) description of life in a terminal cancer ward,

To patients it means much when doctors and nurses know how to handle their wounds competently and without fear. The nurse patiently washing a dilapidated patient, changing his clothes, is also the only one who dares touch him without disgust or fear, who quietly and competently handles the body

which so torments and frightens the patient....[and who] knows how to deal skilfully with the wounds and lumps, in doing so liberating the patients for the moment from their isolation.

A belief in something or someone can often provide a cancer victim with a sense of control in his or her life. A trust in physicians, support groups, specialists and social workers can provide women with the encouragement to get questions answered, to participate actively in treatment decisions, and to consider alternatives carefully.

Family and friends, offer a source of comfort from the despair and horror of being unwell. Having someone to turn to during times of hardship and sorrow can promote a feeling of security within. Being able to openly discuss fears with loved ones can help women to unburden anxious thoughts that lead to intense suffering (Gillian 1982). Spiegel (1999:375) asserts, 'open family exploration of fears and concerns actually helps patients cope better. Having an opportunity to ventilate anxiety, anticipate and plan for future problems, and feel understood and cared for at times of stress reduces distress'. Further, family members and friends, who provide assistance at a physical level, can also facilitate coping. Family and friends may give up jobs or take time off from work to care for cancer patients. Driving a friend to the hospital to receive treatment, cooking and cleaning for a sister who is too sick to move, or buying groceries for a mother who is incapable of shopping, can help breast cancer sufferers feel loved and supported. When faced with a crisis, people need to feel that they can depend upon those closest to them to help them recover. A close support network made up of individuals who are willing to help a woman's chances of recovery, who offer moral support, compassion and empathy, can have a significant impact on the healing process.

Structural elements such as a person's social position and relationships in the work place can also influence the way in which disease is managed (Baider *et al.* 1996).

Salespersons for instance who are constantly bombarded with negative customers may internalise this negativity as a reflection of their competence in their field of employment (Freund and McGuire 1991:101). Indeed such experiences may in turn cause a salesperson to question his or her skills and the ability to work effectively. The professional environment can play a role in strengthening or weakening a breast cancer victim's attitudes to recovery. Research carried out by Bloom and Spiegel (1984) indicates that emotional support is strongly related to the patients' outlook on life and their social setting. Well-being in the lives of breast cancer victims can be related to self-perceptions in a cultural setting alongside the ability to feel safe and secure in a working environment. Work environments that promote a positive atmosphere whereby employees are treated fairly and without prejudice, can impact upon the degree to which an individual copes with illness and disease.

The institution of religion sets up certain codes of interpreting life experiences. People interpret social events through a system of shared ideas, concepts and rules. Religion perpetuates a set of guidelines which members inherit. These guidelines, or codes of conduct, tell individuals how to view the world, how to experience it emotionally and how to relate to particular situations. Thus, understanding disease and coming to grips with chronic illness can be largely influenced by religion (Levin and Schiller 1987). But, religion is only one component of a complex mix of influences on what people believe and how they live their lives. Nonetheless it plays a major role in influencing how individuals cope with traumatic life events. The role of religion in facilitating coping is discussed in more detail in the latter part of this chapter.

Goffman (1963:11) argues that social networks influence and define human behaviour; 'society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these

categories'. Within the boundaries of social settings, individuals play out certain roles in order to fit in. Such roles can be interpreted through language, customs, rituals, clothing and actions. Goffman believes that each role requires a certain kind of performance; individuals take on the facade of actors in their attempts to acquire acceptance and elicit the desired responses from others. Impression management, according to Goffman, is dependant on an individual's ability to successfully play out his or her role and to understand the expected codes of behaviour. As Goffman (1969:41) describes it, 'much of the activity during an encounter can be understood as an effort on everyone's part to get through the occasion and all the unanticipated and unintentional events that can cast participants in an undesirable light, without disrupting the relationships of participants'.

Yet, in the event of cancer striking, impression management and how others perceive an individual, can be tarnished. Diseases such as cancer can be distinguished by their mark upon bodily parts. The loss of hair and the decay of bodily tissue can lead to individuals being stigmatised because of their illness. Goffman (1963) describes those individuals who display characteristics that are stigmatising, that cannot be hidden or disguised, as discredited. Goffman (1963:15) writes,

By definition, of course we believe the person with a stigma is not quite human. On the assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalising an animosity based on other differences.... We use specific stigma terms such as cripple, bastard, moron in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning.

Reputations are soon damaged when an individual is branded as incomplete or defective. A stigmatised individual cannot only face problems of 'impression management', but will often find coping difficult. Thus, coping with illness is both a social and biological construct.

The central premise of Parsons' (1951) concept of the sick role is that there is a distinction between the biological basis of illness and its social basis. He believes that when one is sick, he or she must contend not only with physical symptoms, but also social constraints. What constitutes illness in any culture will therefore be attached to the norms and values that prevail (Parsons 1951). The way women cope with breast cancer and the degree to which women feel content with the world and themselves, is largely due to their relationship with social domains. Social networks play a vital role in how women will experience the process of getting well or dying (Nelles *et al.* 1991). How competent and capable women feel about managing their sickness will depend very much on both the extent to which various social interactions validate or affirm a sense of 'self' and 'social positioning' (Pedro 2001). Thus, medical professionals, family and friends, work environments and support groups assist in the formation of meanings attached to health and illness.

McGuire (1981), like Durkheim (1965), asserts that having an interpretative meaning system allows individuals to understand their place within society. She writes,

A meaning system informs the individual as to what 'kind' of person one is, the importance of the roles one performs, the purpose of the events one participates in, and the significance of being who one is. A meaning system in other words, makes sense of one's identity and social being. (1981:24)

Meaning and purpose in life refers to the extent to which individuals believe that their life is worthwhile and precious. Indeed, cancer survivors often express that, after facing a life-threatening illness, they not only better appreciate their lives, but are able to view their lifestyles with more meaning and satisfaction (O'Connor and Wicker 1995). Such an outlook to life is helpful in maintaining a positive attitude to recovery from illness. Cancer victims, who are able to incorporate their experiences, with a view to restructuring life's priorities and establishing meaning in their suffering, can embrace life in a sacred way (Cope 1994; O'Connor *et al.* 1990; Wyatt *et al.* 1993). Tsongas (1992) writes of his experience with cancer believing it to have given him an

appreciation for life, 'the cancer freed me,...it freed me. I have learned how to live and how to count each day. And to value that day' (p.18). Such a feeling of life enhancement is echoed in other people who have a life-threatening illness. An author, infected with the HIV virus wrote, 'HIV has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with divine things' (Matousek 1993:104). For both these individuals it can be said that finding meaning in the experience of illness has allowed them to construct new experiences and perspectives on life. People, whose lives are void of any meaning or purpose, may have to deal with feelings of emptiness or lack of direction. One needs only to read texts such as *The Outsider* (1983), *Heart of Darkness* (1983) and *Waiting for Godot* (1954) to understand the relevance of substance and direction in the human life span. In the case of an illness such as cancer, acceptance, coping and effectively dealing with this disease may be largely reflective upon the future goals that are set.

Coping with breast cancer can be linked to Durkheim's theory of the importance of social integration. Breast cancer poses unique concerns for women in that they must not only face issues of pain and suffering, but also issues linked to sexual identity, body image and female attractiveness. Coming to terms with a significant change in physical health and appearance can mean an enormous amount of disruption in areas such as self-esteem, identity, relationships, lifestyles, and everyday patterns of social conduct (Clarke 1990). Durkheim would view being tied to a social organisation as being essential to women's abilities to deal with breast cancer. A social organisation that provides women with support and acceptance from a Durkheimian perspective would most likely empower women to cope better with fears tied to illness. The importance of religion for example can be seen here. Does religion offer relief from suffering in the face of breast cancer? Does religion facilitate

coping amongst women plagued with the disease? The next section looks at such questions in more detail.

### **Religion and Coping with Cancer.**

Religion is often viewed as a potentially adaptive resource for coping with negative life events. For many women diagnosed with breast cancer, religion may provide a sense of hope, feelings of intimacy with others, a sense of comfort within and closeness with God. In research carried out by Jenkins and Pargament (1988), it was found that cancer patients who reported that God was in control of their lives were appraised by their nurses as being less upset and having a higher self-esteem. Similarly, in a study of individuals with advanced cancer carried out by Yates *et al.* (1981), questionnaires administered to seventy-one patients showed that about half the patients regarded church or religion as important in their lives. Therefore, religious beliefs can precipitate feelings of greater happiness and less emotional and psychological pain. When confronted with challenging life events women may feel that otherwise uncontrollable situations, such as terminal illness, may be dealt with by religious practices such as prayer (Collipp 1969). In the case of cancer, which is often perceived by people as tantamount to a death sentence, a sense of inherent meaningfulness and purpose in living may be reached. When individuals rely upon and trust in a religious dimension, coping can be seen in an encouraging and hopeful light (Balk 1983; Bulman and Wortman 1977; Conway 1985/1986).

Theory suggests that religion serves to provide meaning to life events; religion maintains or enhances one's sense of control during difficult times and increases self-esteem in the face of disaster and misfortune (Berger 1970; Durkheim 1965; Klenow 1991/92; Spilka *et al.* 1985). There is some evidence that suggests that religious beliefs are particularly helpful in coping with high stress situations such as depression or mortality (Ferraro and Kelley-Moore 2000; Maton 1989; Zucherman *et*

al. 1984). Spilka and his co-workers, Hood and Gorsuch (1985) assert that during distressful times, religion is seen as a window to providing hope, comfort and optimism. Further, they argue that religious beliefs are a vital force in motivating individuals to comprehend and take control of negative encounters in life. When a religious dimension is added to the coping experience, individuals can feel a sense of confidence about their world. They write,

Religion is thus a source of meaning, an agency of control for people in worship and prayer, and through the provision of meaning and capability, self-esteem is maintained and enhanced in the face of threat and insecurity. (p.21)

Thus, Gorsuch, Hood and Spilka see religion as playing a major part in offering insight to human struggles. In doing so religion provides a sense of security for the person faced with illness and disease. Through scriptures, biblical readings, ceremonies and prayers, people are given a means of taking control over crisis-laden-events. Possible shortcomings, emotional distress and affliction can be triumphed when a divine source is relied upon.

According to Yinger, unforeseen circumstances causing great pain and terror are bearable when society furnishes its members with beliefs and practices that make human tragedies endurable. He states (1970:7),

Religion, then, can be defined as a system of beliefs and practices by means of which a group of people struggles with these ultimate problems of human life. It expresses their refusal to capitulate death, to give in the face of frustration, to allow hostility to tear apart their human associations.

Thus, Yinger views religion as being important in assisting individuals through times of despair and inner turmoil. In the presence of disastrous circumstances, feelings of not being in control, friction in relationships with others and intense anger are manageable when religion is clutched on to. During times of woe and despair, having a religious outlook to life allows many people to encompass a sense of tranquillity and spiritual comfort. As Yinger sees it,

A society that did not furnish its members with beliefs and practices that gave them a means to deal with these ultimate problems would have to struggle with an enormous burden of tragedy unallayed and hostility unrestrained — if indeed it could survive at all. (1970:8)

A religious culture is seen by Yinger to provide human beings with a powerful source to interpret and deal with illness, misfortune and death. He believes that individuals are 'impelled to try and discover some meaning in what seems to be senseless suffering, some road to salvation through the obstacles of human life' (1970:7). Religious culture can therefore be seen as a medium through which salvation from pain and suffering is achievable. Through socially constructed religious frameworks, women with breast cancer can be given a basis on which to re-evaluate, assess and come to terms with their illness.

Kushner (1981) details the importance of religious beliefs in helping people confront illness and death. He believes religion is essential in that it operates as a source of comfort and peace in the event of disaster. When people feel alone and singled out by fate, when disease plagues healthy bodies, religious beliefs provide support and continuity. During times of hardship, Kushner sees religion as an outlet which enables people to share their grief and suffering with others. Through the religious congregation, human troubles are shared with the community. Rituals and fellowships, parishioners and congregations give suffering individuals a source of comfort. In the group situation, grieving and distraught individuals are given an opportunity to express their misfortune through prayers and worship. Parishioners are not only in touch with God, but also in touch with one another. As a result of this, victims of suffering are able to rely upon a collective force in which to regain a sense of control and composure in their lives. Kushner (1981:120-121) states,

And when the mourner attends services to recite the Mourners' Kaddish, the prayer recited for a year after a death, he feels the context of a supportive, sympathetic congregation around him. He sees and hears other mourners, bereaved even as he is, and he feels less singled out by adverse fate. He is comforted by their presence, by his being accepted and consoled by the

community rather than being shunned as a victim whom God has seen fit to punish.

Like Durkheim (1965), Kushner views the institution of religion and its binding collectivity as a vital force in generating emotional strength during times of bereavement, illness and death.

Religiosity, or an individual's beliefs and behaviours in relation to the supernatural, has been linked to recovery from and coping with breast cancer (Brandt 1987; Johnson and Spilka 1991). In the case of terminal cancer, living the last few months in a state of religious well-being, is of the utmost importance for many people. Dr Beverly Dixon, an Anglican laywoman, academic and author, is an example of a woman who, when diagnosed with bone marrow cancer, chose not the option of science and technology. Instead, 'preferring not to wreck the quality of her remaining time' (Porter 1987:16), her last months were spent preparing for her death, writing last farewells to friends and family and facing her final spiritual journey. In an interview she stated, 'I believe that there is a time when it is appropriate to fight, and when perhaps healing services are right, and that there is a time to accept something as God's will and move through a process. My judgement is that it is God's will for me to accept' (p.16). Dr Beverly Dixon was more concerned with treasuring the time she had left, rather than prolonging her life for a short period of time. Instead of seeking medical treatment that would allow her to live longer, the dying process was embraced, accepted and attributed to God's will. When faced with a terminal illness religious faith can become essential for coping with the dying process. Further, strong religious faith can become a sound basis for positive thinking. Positive thinking does not always have to be aligned with a possible cure for disease, or a miracle. Hope that the day ahead will be a good day, hope that special moments with family and friends will be encountered, hope that God is near and will be a guiding force

when the moment of death arrives, assist in providing meaning and purpose when life is limited.

Absent from the empirical study of religion in cancer has been a guiding framework which illustrates the importance of religious beliefs and faith during periods of despair and chaos. Even major research programs on breast cancer have ignored personal faith as a potentially significant variable to effective coping (Taylor 1983). Examinations of faith as a means of coming to terms with breast cancer have tended to be too global. Most researchers have attempted to embrace notions of religious institutions as a means of explaining coping strategies, without taking into consideration the impact of faith on healing. As this thesis concerns itself with the role of faith in providing a means of coping with illness, there is a need to examine what has already been written on faith so far. Reliance on brief self-report questionnaires and surveys, or on gatekeepers in research settings such as physicians, nurses and administrators, should not be the basis for understanding how faith facilitates coping. In order to understand the place of faith in women's lives, this term needs to be explored outside the secular frameworks it is often ascribed to.

Jenkins and Pargament (1995:16) make the point that 'despite the presence of evidence that supports religion as an active mode of coping, one must recognise that religion can be used in a variety of ways and thus defies easy categorization'. Consequently, it is necessary to examine beliefs and practices, faith and spirituality, outside the traditionally defined religious sphere. More useful conceptualisations of faith are needed if there is to be greater insight into the metaphysical experiences of women with breast cancer. Bearing this in mind, this next section attempts to focus on the place of faith in sociological research.

## **The Place of Faith and Breast Cancer in Sociological Research.**

Sociological writings have rarely considered the impact of faith in helping women to cope with breast cancer. While sociologists, psychologists, theologians and other academics have researched and theorised the importance of religion, little has been written on the role of faith during times of crisis. Further, despite the value of religion in cancer-related situations, little systematic research has been done in connection with faith, breast cancer and women. Instead, studies of breast cancer have used religion in 'an ancillary fashion, looking at factors such as church attendance or religious affiliation and their relationship to relatively global indices of patient functioning such as mood' (Jenkins 1991:92).

Because social networks are given a tremendous amount of attention in studies of coping strategies used by cancer victims, writings attempting to conceptualise the role of faith in providing meaning, maintaining or enhancing one's sense of control and supporting self-esteem, have been somewhat ignored. An editor's comment in a sociological journal detailed that little has been done to make sense of religious faith and practice in everyday life. His comments, which follow, can be attributed to the limited body of research conducted on the function of spiritual support and personal faith. Calhoun states,

Theorists have written quite a lot about secularization, but rather less about faith. Certainly there is a lot of good sociology of religion, much of it theoretically serious and indeed innovative. But amid our attempts to reconcile action and structure, to grapple with embodiment, to rethink culture and social organization in light of gender, to trace networks of power, and to conceptualize the rise and transformation of the capitalist world system, have we done enough to make sense of religious faith and practice?...Are we able to rethink our theoretical categories in a way that allow faith to be something other than residual? (1997:1)

Calhoun is aware of the importance of understanding the impact and significance of faith in all domains of social life and practice. He sees it as essential that contemporary sociological research does not simply aim at readdressing what others

have already said; it should not simply limit itself to 'traditional' sociological domains of inquiry or paradigms (p.2). Most religious studies on the area of health and illness are examinations of social behaviour through variables such as average religious denomination, church membership, or single item scales such as 'How religious are you?' or 'The role of church attendance as a religious activity' (Cook 2000; Fabricatore 2000; Jenkins and Paragament 1995; Long Marler and Hadaway 1999). The outcome of studies focusing on various quantitative, rational and measurable facets of the sociology of illness is that extensive empirical investigations have dominated this field. Subsequently, 'less research has been concerned with the possible consequences religious commitment has for subjective feeling-states...eg life satisfaction, personal morale, or anxiety' (Petersen and Roy 1985:49).

In the absence of frameworks that consider the role of faith in the presence of disease, there is no clear foundation for conceptualising emotional and reflective contemplation in the face of illness. An objective bearing to research into the sociology of illness has meant a peripheral approach to the ways in which faith is expressed in particular life situations. Further, as stated earlier, religious writings have also failed in their attempts to highlight the human experience from the perspective of 'the whole person' (McGuire 1996:102). While all these studies display a considerable amount of insight into the importance of religion in helping individuals to overcome disease and sickness, thesis writers on the role of faith have noted little during hardship and tragedy.

Certainly, there has been a lot of good sociology of religion emerging for such papers, yet this has come at a great cost to making sense of religious faith and practice. A global interpretation of religion has also meant that different strategies, open to religious social theorists are inadequate in explaining 'both the persistence of faith and the ebbs and flows of religiosity' (Calhoun 1997). Consequently, if we are to

understand the impact and significance of faith in the lives of women with breast cancer who are researched in this thesis, the word faith needs to be addressed on its own terms. Faith needs to be approached in light of a historical, social and cultural context. This then brings us to our next section, which defines 'faith' and 'spirituality'. Further, this section investigates the limited body of research on women with breast cancer and their use of faith as a means of coming to terms with their illness.

### **The Meaning of Spirituality.**

Like faith, spirituality has myriad definitions. As stated in one journal article, 'exactly what spirituality means has remained rather amorphous' (Martsof and Mickley 1998). This section aims to define spirituality for the purpose of this thesis. Because there has been a lack of conceptual clarity in the term spirituality, the following discussion attempts to shed light into not only what spirituality means, but also its place in contemporary society.

Johnson, a Jungian analyst, believed this story to be one of Jung's favourites,

The water of life, wishing to make itself known on the face of the earth, bubbled up in an artesian well and flowed without effort or limit. People came to drink of the magic water and were nourished by it, since it was so clean and pure and invigorating. But, humankind was not content to leave things in this Edenic state. Gradually they began to fence the well, charge admission, claim ownership of the property around it, and make elaborate laws as to who could come to the well, put locks on the gates. Soon the well was the property of the powerful and the elite. The water was angry and offended; it stopped flowing and began to bubble up in another place. The people who owned the property around the first well were so engrossed in their power systems and ownership that they did not notice that the water had vanished. They continued selling the nonexistent water, and few people noticed that the true power was gone. But some dissatisfied people searched with great courage and found the new artesian well. Soon that well was under the control of the property of owners, and the same fate overtook it. The spring took itself to yet another place and this had been going on throughout the recorded history. (*cited in Elkins 1998:23*)

Clearly this story aims to make clear the notion that there is a difference between religion and spirituality. This story implies that religion is man-made; religion is a

social organisation that seeks to regulate and rationalise the beliefs of its followers. Further, who is permitted access into religious realms is tightly monitored — not everyone is permitted to drink from 'the water of life'. In placing 'locks on the gates', in 'charging an entrance fee', the power of individuals to pursue their own spiritual journey, is taken away; the spiritual seeker will only be accepted if he or she chooses to abide by the rules that have been set. As a consequence of placing restraints upon religion, this story tells us that people have chosen to move on with the desire to find other sacred wells. Further, religious members who have once been permitted entry into these sacred sites also move on. They do so upon realising that their well has dried up and there is no magic left. These members seek to find the same magic that once 'nourished them' and 'sustained their inner being'.

New Age, is a term that mirrors contemporary society's search for a soul, or as the story states, the search for 'new wells'. As one writer outlines,

The New Age movements were primarily spirit movements. They were about ascending, growing, actualizing, and expanding...The spiritual revolution is part of a much larger cultural *zeitgeist* that has been gathering force for centuries and is now sweeping Western society into a new world and towards a new kind of spirituality. (Elkins 1998)

New Age movements bring with them industries that offer consumers a way into finding their own spiritual dimension. Inspirational books can now be brought over a counter. Workshops on meditation, yoga and tai chi can also be booked at New Age stores. Literature on how to initiate outer body experiences, with titles such as 'How to meet your guardian angel' and 'How to find the spirit within', offer consumers a chance to find new symbols for the sacred. While browsing through these New Age stores, consumers are able to take in the variety of aromatic smells that float through the air — they can also listen to enchanting music that seeks to take them to far off exotic places. This self-orientated approach to reaching a spiritual state of existence is on the market and is not limited by religious discourse that requires bible studies

and communion. Rather the modern spiritual experience can be obtained providing one has three things; money, persistence and a desire to become spiritual.

Wuthnow (1998) examines the changes that have taken place in the spiritual lives of Americans over the last forty years explaining not only how the role of religion has changed in American society, but also what has happened as a result of these changes. His thesis, which is supported by two hundred in-depth interviews, is that, in the last half of the century, Americans have drifted from their attachments to traditional churches and synagogues. What has resulted is a more individual and rigorous search for a spiritual state of existing. Wuthnow outlines that spirituality in the last forty years has moved through different stages. Spirituality in America has shifted from one of "dwelling" to one of "seeking". Wuthnow sees Americans as more individualistic in the pursuit of the divine. No longer are Americans restricted to fundamental religious sites to achieve a state of spiritual well-being. Americans now are able to self-direct their own paths in order to reach enlightenment. Further, as Wuthnow points out, today many individuals seek the mystic experience and will go to all lengths to find it. He writes,

The freedom that living in a secure community of like-minded individuals offered was gradually replaced by a freedom to exercise choice in a marketplace of ideas and life-styles. Freedom of choice was attractive to those who in fact were confronted with an immense array of alternatives...In the process, freedom came to mean paying attention to the inner voices of feelings, and freedom of choice meant exposing oneself to alternative experiences that would help develop these voices. (1998:83)

Wuthnow sees spirituality in contemporary society as being noninstitutionalised and seeker-orientated, largely built on choice and 'small, easy to consume packages' (p.84). There has also been what he sees as a craze to find a spiritual-self according to individually set rules where the aim is to re-discover the constructs of personal growth and analysis (p.224).

Wuthnow outlines that modern society has a desire for the religious or spiritual experience. The narratives he presents detail people's experiences with angels, ghosts, the mystic and inner-peace. Most importantly, Wuthnow comments that the individual who seeks to achieve a state of spirituality must prepare himself or herself in a particular way. Practice is the key word that he uses. The individual, in search of the sacred, must devote a reasonable amount of time to performing spiritual tasks in a given day. He writes,

Spirituality is not just communal or else trivial. It can also be quite serious, practiced deliberately by individuals who draw on resources from other individuals and from organizations and yet who are not fully submerged in any one community. To say that spirituality is practiced means that people engage intentionally in activities that deepen their relationship to the sacred. Often they do so over long periods of time and devote significant amounts of energy to these activities. In most cases, prayer and devotional reading are important; and in many cases, these activities are life transforming, causing people to engage in service to others and to lead their lives in a worshipful manner. (p.169)

There must therefore be a sustained commitment by the believer if spiritual attainment is to be achieved. Through partaking in rituals, attending workshops, listening to music, and reading the relevant literature, the seeker is closer to a path of mystic power. Further, as Wuthnow points out, there must be within the believer a desire to live a disciplined life, to want to be good, kind and generous,

Having spiritual discipline does not mean following a set of divinely ordained moral rules; it means having faith that there are right ways to live. Leading a disciplined life thus means having faith in the existence of goodness or at least in the possibility of its existence. (p.103)

Wuthnow sees 'good living' and 'common sense' (*ibid*) as being essential in the maintenance of a spiritual outlook to life. Believing in the absolute goodness of life and the world is necessary if there is to be a true spiritual transformation.

Davie (1990, 1994), like Wuthnow, believes that the sacred in contemporary society can be found and expressed in a variety of ways. For instance, Davie has argued that while there has been a decrease in church attendance in Britain since the

1960's, there has evolved new ways of creating symbols for religious belief. She writes, 'Complacency in the 1950's gave way to a radicalism dominated by the values of the secular world. But, this in turn led, eventually, to a renewed emphasis on the sacred, sometimes in unconventional forms' (1994:42). Davie recognises that with secularization there has been an expression of belief in private domains—the English believe that, without necessarily belonging to an established church, their desire to find religiosity continues regardless of the absence of institutional ties. 'The crucial point to grasp' Davie writes, 'is that religiosity persists despite the obvious drop in practice. The sacred does not disappear—indeed in many ways it is becoming more rather than less prevalent in contemporary society' (p.43). She makes the point that each person's 'holy ground', can be expressed in various ways and that secularisation has provided a framework for the resurgence of religious belief. While the evidence is clear that there is a decrease in the participation of traditional religious practices in Britain, there has not been a decline in the willingness of people to believe in a divine force.

Davie looks to the New Age movement as a means of identifying modernity's separation from institutional religion, to spirituality. Davie views the New Age as 'a phenomenon that affirms the continuing significance of the sacred in contemporary society but in far from conventional forms' (1994:41). This separation of spirituality from religion is a sociological phenomenon worth inspecting. The upsurge of New Age stores has provided individuals with an abundance of spiritual literature to draw upon during their times of need. Davie is only too aware of this and questions the point at which New Age industries remain true to the values it seeks to promote. 'Interestingly, the New Age also embodies the dilemma posed at the beginning of this section: it both feeds on a consumer society (marketing its own particular and infinitely varied products), but at the same time rejects many of the assumptions that underpin contemporary materialism' (1994:42). For instance, the *New Age Journal*

was firstly introduced in 1983. By the end of the twentieth century there were over 200,000 prescribers. The cash flow from this journal meant a huge salary cheque for the founders of this journal (Elkins 1998:17). Yet, whilst Davie sheds light into the contradiction of New Age stores, she is aware of the positive influences these stores have brought about. People now have access to a wide range of spiritual doctrines, originating from the Far East, to the Southern Planes of South America. Through tapes, videos, books and seminars, people can attain a spiritual state of being, without having to go to church.

McGuire (1993:148-149) also outlines the charismatic force of New Age movements in promoting an alternative road to healing. She writes,

New Age groups are eclectic; they borrow images, myths, symbols, rituals and healing practices from such diverse sources as Asian traditions, Christianity, the Western occult traditions, nature religions, Native American and other indigenous traditions...some eclecticism is guided by a central underlying idea, such as the nature and use of healing energy, which believers hold as an alternative to the biological model.

Further, as McGuire points out, New Age movements encourage spiritual seekers to get in tune with 'mind, body and spirit' (p.148) believing this to be essential for emotional, physical, spiritual and psychological well-being. In looking beyond a rational approach to healing, in choosing to trust in an alternative way of feeling and thinking, New Age movements offer individuals a chance to search for the sacred in a creative and spontaneous way.

McGuire (1988) examines the role of alternative healing practises in American culture. In her study of the various techniques adopted by Americans in their search for well-being she comments that there is an increasing interest in non-biomedical approaches. Further, McGuire states that Americans of middle class background had the highest rate of seeking unconventional therapy. Medical physicians were seen to lack a holistic approach to healing.

Most contemporary Western physicians limit their help to the cure of the disease—a biological disorder. They are generally unprepared to heal illness—the way the ill person experiences his or her disorder, in a given social and cultural context. Alternative healing, by contrast, appears generally to address illness more than the disease. (p.6)

McGuire therefore writes of the importance of holistic healing in the lives of suburbanites; the psychological, emotional, physical and spiritual domains of an individual's makeup co-exist to create a strong sense of healing power. One woman in her study states the following,

I think there is so much healing that comes from a person if they just know how to really source into it, that they can be trained...or shown how to go to your different levels of strength. I believe in medicine; I'm a nurse and of course, medicine definitely has its place. But I think so many times...if you step back from your situation when you're not feeling well, whether it's aches and pains kinds of thing, if you can assess your whole emotional, psychological, nutritional—the whole thing—and work at that, you can then encourage your own healing. (p.109)

McGuire's (1988) study into spiritual healing groups in America provides an insight into the power of ritual behaviours as a means of acquiring a sense of personal well-being. New Age workshops and programs on spirituality and healing offer alternative paths to acquiring emotional stability. The use of non-traditional sources as a means of coping with breast cancer is a theme that is given consideration in chapter seven. The role of holistic healing as a tool for coping with breast cancer is also examined here.

A more universal view of the meaning of spiritual beliefs is that they provide a frame of reference for self, and relationships with others, which can help a person to transcend some of the tragic conditions of his or her existence (Hall 1986). Hall found that those individuals, who increase their commitment to spiritual beliefs as a means of coping with crisis situations, increase their opportunities for spiritual growth (p.9). The spiritual dimension of human beings encompasses the need for finding

satisfactory answers to problems encountered in life.<sup>2</sup> Spiritual beliefs can be seen as a keystone to effectively coping with questions about the meaning of one's life, changes in significant relationships, illness and tragedy (Burkhardt and Nagai-Jacobson 1985).

Spiritual beliefs are ordered to create a meaningful view of the universe, and individuals identify with the values they select as being most significant for them. Hillman (1989) and Moore (1996) see the adoption of spiritual beliefs as a journey of "resacralization" that leads the individual to find strength from not only within but from external forces as well. Wink (1999:76) comments on this way of attaining a divine intervention by stating,

In this view, the goal of each individual is to embark on a personal journey with the aim of discovering the transcendent in everyday life and in all human relations. Compared to the ways, in which spirituality was conceptualized in the past, the emphasis shifts away from a unified sense of the self to a multiplicity of selves, each involved in a meaningful (spiritual) relation with the surrounding environment. In other words the aim of spiritual growth is to develop an ability to find the sacred at every point in time and in everything one does.

Spirituality in this sense is attained when individuals are able to find meaning in their ordinary affairs and in the social environment they are entwined within. Thus, the

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<sup>2</sup> The novels of Dostoyevsky are replete with terror encountered by men and women at the hands of tragedy. His characters all mirror a real aspect of human existence—that men and women unable to come to grips with crisis through their spiritual beliefs, or religious affiliations, come face to face with the horror of pain, death and immortality. His texts, *Crime and Punishment* (1991), *Notes From The Underground* (1972), *The Devils* (1971), *The Brothers Karamazov* (1958), focus on the decline of the human spirit when it is unable to transcend human powerlessness over time and nature.

Through his use of characters, Dostoyevsky fuses decaying towns with displaced societies, highlighting the need for religion and faith to make sense of the mysteries of life and death. Further, he sees religious encounters, shared expressions, symbols and sacred orders as creating a sense of well-being for the individual suffering emotional turmoil. This is seen clearly in his text, *Crime and Punishment*. Raskolnikov, the main character in the text, after having killed an old woman and her sister, searches for a redeeming force to overshadow his feelings of guilt and estrangement. He is advised by Sonia, a prostitute, from a broken home, to restore his belief in God and religion. When the time comes for Raskolnikov to make atonement for having murdered, Sonia states the following,

Go immediately, this very moment, go and stand at the cross roads, bow down, first kiss the ground that you've desecrated, and then bow to the whole world, to all four points of the compass and tell everyone, out loud, "I have killed!" Then God will send you life again... You must accept suffering and redeem yourself by it. (1991:488-489)

Dostoyevsky, thus sees religious encounters and strong spiritual belief as imperative to creating a sense of well-being for the believer. People who are faced with poverty, murder, chaos and disorder, can be given a sense of support in the presence of religious doctrines and faith. Crisis and human suffering, in this instance is better dealt with when one is able to rely on sacred domains for strength and courage.

sacred can be found in various facets of our lives and can lead a person to encounter feelings of joy, hope and love.

For the purpose of this thesis, I refer to Bouma's (2000:388) definition of spirituality as a way of interpreting this theme within the contexts of my study.

Spirituality refers to our experiences of and ways of relating to that which is 'more', beyond and 'greater than' the ordinary, the material, the everyday aspects of life. Spirituality involves those experiences, things, ideas, actions and beliefs that give life meaning. In our spirituality we mark and celebrate what we consider to be ultimately important, worth sacrifice and placed first in our priorities. Spirituality focuses on what enhances the quality of our living by relating us to greater beauty, truth, wisdom and power. In our spiritual life we relate the here and now of our ordinary life to the transcendent, to ennobling values, inspiring beauties and awesome powers.

Spirituality may not be linked to religious beliefs and it may be from the ordinary, everyday affairs, that individuals are able to attain a divine presence in their lives (Granstrom 1985). Thus, spirituality involves a desire to build a relationship with the transcendent. In the establishment of a sacred connection with the transcendent the individual is inspired and reassured that life is purposeful and meaningful.

### **The Meaning of Faith.**

There are many different conceptions of faith. As Tillich (1957) writes, 'there is hardly a word in the religious language, both theological and popular, which is subject to more misunderstandings, distortions and questionable definitions than the word faith' (p.7). The faith of a Polish priest is not the same as the faith of a Buddhist monk, and neither is it the same as the faith of a Rabbi, a Sikh guru, or a Jehovah's Witness. Thus, faith encompasses a variety of meanings for all members of society. In addition, as Sessions (1994) points out, faiths differ in many ways in that people have faith in numerous things and objects. Individuals have varying degrees or amounts of faith alongside different ways of expressing their faith. Moreover, faith is not always attached to the religious — faith can be placed in scientific institutions, other human

beings, animals, art and business enterprises. Consequently, meanings attached to faith, 'involve different conceptions; there are different views as to what it is to have faith, what the essential features of faith are, what faith consists in, what faith is' (Sessions 1994:2).

It is through faith that an individual is able to go beyond everyday life into spiritual dimensions of feeling and thinking. When they have faith, individuals are able to extend themselves beyond personal concern. Broader life perspectives, activities and a purpose in existence are maintained and one's place in the world is made apparent. Faith can also find its expression in religious as well as non-religious symbolism. Whether we are Christians, Jews, unbelievers, sociologists, or pacifists, we all need to feel that things matter in our lives, that tomorrow will be a good day and that life is worth living. Through personal faith people are also able to maintain feelings of self-worth and importance.

Faith is a total and centred act of the personal self, the act of unconditional, infinite and ultimate concern. Galloway (1967:13) believes that although the word faith is used in a great variety of senses, there are fundamentally two types of usage of this word. First, faith is seen as a belief in certain propositions on the basis of the irrational, or on the basis of inadequate evidence. Second, faith is understood as a distinctive quality of personal life involving total commitment and trust. Faith, then, can be understood as a state of existing which is not bound by ethics and dogmas. As Hughes and Blombery (1990) point out, faith does not bring knowledge or a higher degree of objective certainty, but involves a relationship with the divine and sacred.

Kierkegaard was a religious thinker who wrote on the meaning of faith. According to Kierkegaard, faith, first and foremost is a self/God relation. This relation is radical and

absolute. Secondly, faith is a self/world relation. In order for individuals to find absolute contentment within, by means of faith, materialistic wealth and worldly possessions must be abandoned. When worldly and materialistic interests are forsaken, faith results.<sup>3</sup> In Kierkegaard's text *The Sickness Unto Death* (1983),

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<sup>3</sup> Soren Kierkegaard, in his text *Fear and Trembling* (1985), concerns himself with this very theme. He distinguishes three major stages of the human condition, which awakens the mind to self-consciousness, to universal consciousness and to the standpoint of absolute thought. Furthermore, in his examination of these three stages, he makes clear the notion that a believer must make a 'leap', a 'movement of passion', if one stage is to be overtaken by the next. The believer must want to move forward. This leap or movement must be a willed self-commitment based purely on choice, not of thought, as the transition to a higher order must be a decision based on soul and passion, rather than the conceptual synthesis of rational thought.

The first stage of the human condition is defined as the aesthetic and it is a level of consciousness where the obtaining of pleasure becomes central to the needs of the individual. In the seeking of pleasure, the aesthetic individual is governed purely by sense, emotion and impulse, desiring to create a world in which beauty and art become the centre focus of existence. Consequently, for the lover of beauty, their sensual desires are not bound by religious beliefs or universal standards, as their absence of faith ensures that they are governed by no restrictions or boundaries. Thus, there exists absolute freedom in all areas of decision-making and in the experiencing of all that can be; the aesthetic individual despises all that would limit his or her choice. However, as Kierkegaard points out,

If there were no external consciousness in a man, if at the bottom of everything there were only a wild ferment, a power that twisting in dark passions produced everything great or inconsequential; if an unfathomable, insatiable emptiness lay hid beneath everything, what would life be then but despair? (1985:490)

Hence upon realising that there can be no salvation or remedy at the level from which they stand, the aesthetic individual is confronted with a 'pit of despair' and risks being engulfed by the absurdity of being. Like Kurtz, in *Heart of Darkness*, who falls prey to the powers of darkness, to the brutal instincts and monstrous passions of humankind, all that remains to be seen is 'The horror! The horror!' (Conrad: 1983:147). Remedy for the individual faced with this state of consciousness comes in two forms; either to remain at this destructive state he or she is presently in, or to 'take a leap', an 'act of self-will', into the next level of consciousness.

The second stage of human consciousness is defined as being the ethical. It is the level at which the individual thinks and behaves within a sphere of moral standards and universal codes of practices. As a consequence to this, individuals must dissolve their willingness to exceed all limitations in their quest for absolute freedom. Kierkegaard describes the moral individual as being typified by Homer's tragic hero Agamemnon, who sacrifices his daughter Iphigenia, to the goddess Artemis, so as to calm the winds and conquer Troy. In this case a king's ethical duty to the safekeeping of his city comes at a cost to the destruction of his daughter, which results in the annihilation of his aesthetic happiness (1985:139). Within the ethical realm, individuals must not only renounce their human pleasures, as seen in the tragedy of Agamemnon, (whose personal happiness must suffer at the hands of killing his child), but must also place limitations and restrictions on the gratification of their instinctual desires.

In his text, *Civilisation and its Discontents* (1963), Freud, like Kierkegaard, highlights the essentiality of enforcing moral and universal values upon the destructive instincts of humankind, believing it to be the only process 'which distinguish our lives from our animal ancestors and which serve two purposes — namely to protect men against nature and to adjust their mutual relations' (p.26). Consequently, the ethical stage of human consciousness enforces a sense of duty and obligation upon the individual, who must surrender his or her innate powers to an authoritative entity, an entity which regulates the social conduct of their very being. This renunciation of individual control thus ensures a sense of protection and safeguarding from the 'horrors' of their very human nature.

Yet, Kierkegaard, believes that the ethical stage can produce what he terms as being the 'tragic hero'. There may come a stage in the individual's life where he or she realises the inability to fulfil a moral law, and remain virtuous at the same time. This is due to guilt and shame, which is enforced by the ethical order upon the social being, which seeks to prevent the power of the individual from establishing itself within a universal domain. When the ethical being is faced with such a dilemma, he or she is confronted with the acceptance or rejection of the stage of faith. Abraham faced such an ethical dilemma and chose the way of faith. Similarly, just as despair takes hold of the aesthetic individual when faced with the nullity of life, and redemption is only obtainable by a movement of passion into the ethical stage, the tragic hero must too perform a leap. This leap of faith is based on spirit and the infinite. It is only in believing that one's duty relates directly to God, that such a 'knighthood' into the next level of consciousness is possible.

Kierkegaard conveys to us the hard fact that faith is a state of existence which is bound by no laws. Further, faith, Kierkegaard says, takes away all the anguish and horror in one's lifetime. He states, 'In such a relation of faith, we come to ourselves as spirit and root out of our existence every trace of despair' (1985:14). Yet, Kierkegaard, unlike Durkheim, or Tillich, views the attainment of faith as being entwined with feelings of dread and fear. He sees a true spiritual state of consciousness as being difficult to achieve by modern standards. Hall (1993:4) comments of Kierkegaard's view of a technical world,

Kierkegaard's critique of the modern age centres on his charge that modernity is essentially faithless, selfless and spiritless. His judgement echoes his modern prophetic predecessor, Pascal, who so incisively recognised that we moderns are restless, rootless, and place less people. (1993:4)

Kierkegaard views Western Society as being spiritless and devoid of any meaning. He believes that technology and scientific rationale have come to dominate all forms of thinking. This has resulted in the destruction of mystical beliefs whereby the modern age has robbed its people of a spiritual existence.

But, how is it then that women living with breast cancer today are able to attain a sense of self-worth in the midst of all this scientific reasoning? No doubt many women with breast cancer would argue that faith is very much alive in their lives. Amidst the development of high-rise buildings, computer games and mobile phones,

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Kierkegaard describes the third and final stage of human consciousness as being the religious. Within this stage the individual has but an absolute duty, an authentic commitment to God. The knight of faith must therefore renounce and surrender his or her humility. Humility is derived from the ethical realm which is the objective, the finite. The religious level in comparison is a more spiritual and deeper state of existence, being the subjective, the infinite. Whilst the spiritual being recognises the contingency and relatively of every 'finite' good, he or she is not subordinate to the worldly controls and objective values of the universal. Rather, true believers are superior to the 'ethical realm' relying on their virtuous self-sufficiency as a means of movement towards faith, spirit and God. It is the belief in 'the absurd', in that which can not be rationalised, manipulated or controlled, that the knight of faith becomes what he or she really is—the individual before God (Mooney 1991:94-95). Such an individual before God is Abraham, 'the father of faith', who must sacrifice all to obtain all. Kierkegaard highlights the biblical story of Abraham in an attempt to justify the qualities needed, if one is ever to be a true follower of faith. In his text *Fear and Trembling*, he makes clear the notion that Abraham attains the religious through the renunciation of the aesthetic and ethical stages. For the sacrifice of Isaac means a destruction of Abraham's personal happiness. With the annihilation of the universal laws 'Thou shalt not kill', in the sacrificing of his son, Abraham pays this price and is a servant of God.

their faith is not destroyed. Faith is the ability to feel happy and content with oneself, regardless of one's surroundings and predicament. Therefore, modern society has an inability to build barriers against true harmony and inner contentment. Faith offers transcendence from the immediate environment and is the all-powerful; faith sustains and energises a wounded spirit and life goes on.

Julian of Norwich was a religious recluse who lived in England during the latter half of the fourteenth century. She was born in 1343 and almost nothing else is known about her except for what she tells us in her book *Revelations (or Showings) of Divine Love*. In this text, Julian of Norwich details that the pains and ambiguities of life can be conquered through the love of God. She is sure that love, attained through the embodiment of God who creates all things, will bring all things to perfection. Her dialectic on faith is that faith grasps the objectively uncertain and affirms it; pain in human lives is overcome and resolved when the gulf between human existence and spiritual existence is bridged. It can be bridged only by a leap of faith, by a voluntary act by which human beings relate themselves to God and in doing so embody a belief that 'all will be well'. It is this faith and the embodiment of God as a self/world relation which leads Julian of Norwich to conclude that all experiences both good and bad, work together in a positive way. This is seen when she proclaims the following,

And it seems to me that this pain is something for a time, for it purges and makes us know ourselves and ask for mercy; for the Passion of our Lord is comfort to us against all of this....And because of the tender love which our good Lord has for all who will be saved, he comforts readily and sweetly, meaning this: It is true that sin is the cause of all this pain, but all will be well, and every kind of thing will be well. (1978:Chapter 27:225)

According to Julian of Norwich, in embracing Christ and his Spirit during times of despair and woe, there is an interaction between suffering and transcendence. We may think of her idea here in more concrete terms. People who are ill may be suddenly aware of their inability to help themselves at all. This brings about fear, but

at the same time, it makes them aware of their dependence upon God. Such awareness in Julian of Norwich's eyes is healthy. To recognise that we are utterly dependent upon God is necessary if we are to truly love God—if we are to truly experience the meaning of inner peace and sanctity during times of hardship and sorrow, sickness and death, we must suffer and in our suffering come to rely on God's goodness. Yet, as stated previously, faith may not necessarily encompass God during tragedy. Julian of Norwich views God as being the primal element in transcending pain and discontent. However, faith can be connected to a state of existing outside of the religious realm. For many people peace and tranquillity is found in all experiences of life; serenity and contentment is not only attained through God. Rather, for many individuals, both good and bad life events are valuable and manageable by those forces which bring hope and comfort to their lives.

Throughout *Revelations* Julian of Norwich makes the observation that only love can produce love. Fear produces only greater fear—unless, in our fear, we turn to God to experience his love. She writes,

We are liable through our feebleness and folly to fall, and we are able through the mercy and grace of the Holy Spirit to rise to greater joy...So this is the remedy, that we acknowledge our wretchedness and flee to our Lord; for always the more abased we are, the more profitable it is for us to touch him. (1978:Chapter 77:329-330)

In projecting herself as a figure of goodness, vibrant with faith and love, Julian of Norwich makes clear the notion that humans can achieve a state of spiritual ecstasy. Further, her teaching is timeless, meeting some of the urgent needs of those individuals seeking spiritual contentment. Numerous people, wanting guidance and answers to crucial problems of spiritual development and contemplative consciousness, find in her writing a path to humility in suffering. Human beings are encouraged by her to experience a sense of calmness and peacefulness in everything that occurs in life.

While, to some degree Kierkegaard may be correct in saying that modern people are somewhat spiritless and alienated from their world and themselves, for women with breast cancer, this may not be entirely true. If we live in an atmosphere of cultural despair, which prevents us from embodying a sense of self and inner contentment, how is it that victims of cancer are able to find inner peace and harmony in the face of sickness and death? Having to experience the dread and fear of dying can, for some cancer patients, open up windows to dimensions of spirituality. These windows may include a perception of life's purposes and directions, a knowledge of a state of existing in which contentment in the midst of disaster is felt. This state for many is attained through having a faith. Is faith a source of hope and comfort for those women with breast cancer who I interview? Possible answers to this question will be offered in chapter seven.

### **Faith, Spirituality and Coping with Cancer.**

Faith and spirituality have received attention in some studies of coping and adjustment in cancer patients. Drawing conclusions from this literature for purposes of further research is difficult because of the lack of explicit paradigms for considering the role of faith in the lives of cancer patients. To understand how cancer patients use faith, one must examine the ways in which this factor may be alien to researchers and clinicians. Most clinicians come from secular backgrounds and tend to be less religious than their clients (Beit-Hallahmi 1992; Larson *et al.* 1986). Similarly, researchers are less likely to acknowledge a belief in afterlife when compared to the general public (Gallup and Proctor 1982). Yet, despite these limitations, the existing literature on faith and spirituality in cancer does provide a basis for understanding its importance in the lives of people.

Whilst science may appear to have all the answers when it comes to its dealings with a diseased body, it cannot fix a diseased mind. With the onset of cancer comes emotional and psychological upheaval that can cause great pain and anxiety for the individual. Consequently, there may often come a time when cancer victims seek more in their lives. In being greeted with a terminal disease, patients faced with the disarray of emotions may opt to finding a place of inner harmony within. Eliopoulos (1999) believes that it is important for individuals to have a link to a spiritual source if these emotions are to be overcome. She details that when a spiritual connection is felt, the individual is able to experience a range of positive experiences. Some of these feelings include a feeling of being watched over, a feeling of being loved and a desire to focus on the positive things in life. Experiencing emotions such as joy, happiness, hope and peace are also commonly encountered by individuals who have a strong relationship with a higher source.

Daaleman (2000) also writes about the importance of spirituality for women with breast cancer. Daaleman believes that spiritual well-being is strongly linked to quality of life. Spirituality can impinge on social supports and methods of coping. He outlines that spirituality may enhance a person's subjective state in four ways. These are,

Promoting a salubrious personal lifestyle that is congruent with religious or personal faith traditions, providing systems of meaning and existential coherence, establishing personal relationships with a divine other, and ensuring social support and integration within a community. (p.26)

O'Connor *et al.* (1990), assessed the relationship of hope to spirituality. Their findings assert that spiritual beliefs inspire a sense of coherence and quality of life in the midst of cancer. They concluded that spirituality and religious practices enabled victims to attain meaning in their lives, which provided direction, motivation and a reason for living. The ability to find purpose and order in life is central to battling illness (Dufault and Martocchio 1985; Herth 1989; Hickey 1989; Miller 1989; Nowotny 1989; Raleigh 1992). Faith can therefore offer individuals a reason for getting up in

the morning and a purpose for moving forward. Taylor (1983) also found that spirituality played a key role in helping patients to feel in control of their illness. This in turn empowered them to make effective decisions about their recovery and management of illness. Spirituality can therefore be seen to play an influential role in how cancer patients cope, accept and re-evaluate their illness.

Steeves and Kahn (1987) were able to closely observe hospice patients who were suffering from terminal illnesses and individuals who were grieving the future loss of their own lives. After a period of time, it was noted that these individuals, in their pain and suffering, were experiencing sensations of being in contact with forces greater than themselves. Such forces fundamentally changed the way they experienced turmoil. In detailing one experience of a man suffering from prostate cancer, they note that listening to music from the 'big band' era made him cheerful. Steeves and Kahn state,

In his contact with the music, he felt as though he had joined with, was in communication with, something large and fine, something good and powerful enough to cause him to experience himself and his suffering in a new way. He was not however, able to define this something. (p.114)

In this instance, it can be said that this man's mood was connected with a form of transcendence. The physical pain encountered by this man, in his state of illness, was over-ridden by an experience of spiritual harmony. He believed that the sounds that he heard from the 'big band' era possessed a quality which enabled him to rise above the dread of his situation. His inner torment became manageable through music and this occurrence allowed him to feel happy. Further, a connection to an enchanting force altered his perceptions of grief. For a short period of time, his sadness disappeared. In the presence of significant encounters, in the embodiment of a connection with a higher power, inner peace and a link with the sacred was felt within.

Post-White *et al.* (1996) indicate that cancer victims who found meaning in their lives through spirituality, faith and religious practices were better equipped to deal with their illness. More than 75% of subjects interviewed indicated that 'spiritual beliefs and faith in God or a higher being were important to their sense of hope.... Most participants felt that faith or a belief in a higher power helped them feel more hopeful' (pp.1575-1577). It may be said that the individual with chronic illness, who moves towards a sense of consciousness entwined in wholeness and transcendence, finding joy, hope and pleasure in the present moment, is better equipped to deal with death. Instead, the individual, confronted with illness, who ignores and denies the reality of the situation at hand, may find it difficult to overcome debilitating emotions such as anger, hurt and a sense of powerlessness. Spirituality can therefore provide meaning in human lives. Meaning can in turn facilitate a positive outlook to coping with a life threatening illness.

Frankl (1959) discusses the importance of finding meaning through suffering in his text *Man's Search For Meaning*. Here he details his dreadful encounters in Auschwitz and the horrors he was forced to witness and face. Whilst, he notes that many others in his situation found themselves unable to make sense of their anguish and torment, he in turn believed that it was his suffering that provided him with a purpose in life. Miserable from cold, physically and emotionally exhausted from hunger and cruelty, he still managed to find meaning and a sense of responsibility in his existence. Even though worldly possessions were stripped from him, even though his entire family, except for his sister, were killed in the gas chambers, life was deemed valuable and worth living. While others in concentration camps thought only of suicide and ending their dreadful circumstances, Frankl was able to rise above his horrific and harrowing experience. In the midst of barbaric murders and acts his main concern was to find existence worth preserving, to view life as being made up of invaluable encounters,

both good and bad. His dealings with suffering in Auschwitz led him to write the following,

It seemed to me that I would die in the near future. In this critical situation, however, my concern was different from that of most of my comrades. Their question was, "Will we survive the camp? For if not this suffering has no meaning." The question, which beset me, was, "Has all this suffering, this dying around us, a meaning? For, if not, then ultimately there is no meaning to survival; for a life whose meaning depends upon such a happenstance—as whether one escapes or not—ultimately would not be worth living at all. (1959:117)

Frankl's philosophy on the necessity to find meaning in the horrors of life occurrences can be linked to faith and women with breast cancer. Women with breast cancer, who are able to make sense of their illness by means of faith, are possibly better equipped to cope with illness. In being able to make sense of one's diseased body, in surpassing the grief of expected death, existence becomes worthwhile and cherished. A sense of coherence in breast cancer provides individuals with the ability to better accept their misfortune. Moreover, to rise above the pain and anguish of cancer is to destroy fears of a senseless death. Thus, believing that the world is still a precious place, regardless of the horrors of disease, is to find meaning in a world full of lived experiences. Further, believing that the existence of human fineness or goodness is above and separate from an individual's fate, enables people to link positive feelings to suffering (Steeves and Kahn 1987).

In *The Meaning and End of Religion* (1962), Smith highlights the importance of faith in human lives.

Faith, then, is a quality of human living. At its best it has taken the form of serenity and courage and loyalty and service: a quiet confidence and joy which enables one to feel at home in the universe, and to find meaning in the world and in one's own life, a meaning that is profound and ultimate, and is stable no matter what may happen to oneself at the level of immediate event. Men and women in this kind of faith face catastrophe and confusion, affluence and sorrow, unperturbed; face opportunity with conviction and drive and face others with cheerful charity. (p.12)

Faith, as Smith sees it, involves a specific way of looking at the world. Through visualising the universe in a confident and trusting manner, a person is able to live in a transcendental way. Further, such confidence in the world, or other external forces, precipitates 'an orientation of the total person, giving purpose and goal to one's hopes and strivings, thoughts and actions' (Fowler 1981:14). Faith shapes the way people present themselves to others and their surrounding environment. To have faith is to believe that there are things in life worth experiencing, treasuring and clutching near. As Kierkegaard (1985) sees it, to have faith is to take a blind leap into the sacred, a leap that rids itself of the ethical and aesthetical demands of life. Wuthnow shares Kierkegaard's view on the importance of working towards faith. In his words, 'faith is no longer something people inherit but something for which they strive. It provides security by giving them resources, by plugging them into the right networks, and by instilling confidence to bargain for what they need' (1998:8).

### **The Interpretation of Faith in this Thesis.**

As I see it, faith is a state of being and not feeling. With faith human existence takes on a harmonious make up and the world is seen as a friendly place. Thus, faith is above all, a pathway that can lead a person to triumph over the evils and torments faced. Faith allows a core orientation of optimism. Faith in a divine presence, a trust in a higher source, can lead an individual to feel a sense of hope when trauma strikes. With faith comes a cosmic confidence that somehow all will be well amidst the suffering and pain encountered in one's lifetime. Thus, faith is something that empowers someone to have a desire to go on; faith encourages a person to face the day against adversity and hardship, to go forward when all else seems lost. When individuals are given a universal reliance that things are not as bad as what they seem, faith generates an underlying mood of expectation and fearlessness.

Julian of Norwich's belief that in the presence of a divine force somehow 'all will be well, and every kind of thing will be well', epitomises the essence of faith. No matter how dreadful a situation may appear, faith offers a form of transcendence from suffering and life continues on. Subsequently, in the midst of physical pain and emotional despair, faith offers a channel into inner peace and harmony. This channel allows for the unburdening of fears linked to illness, death and the life after. Consequently, tragedy and frustration, uncertainty and misfortune, evil and bewilderment can be overcome and fought. Finding a central meaning in life, despite the suffering and the succession of affliction and catastrophes helps individuals to live in a sacred and special way.

Faith, as Fowler (1981:5) puts it, 'is a way of moving into the force fields of our lives' and of finding 'an overarching, integrating and grounding trust in a centre of value and power sufficiently worthy to give our lives unity and meaning'. Faith then helps to re-establish order by taking control of uncertainties and contingencies. The tragedy of death, the destructive nature of illness, the devastation of cancer, can all be met with a confident spirit. This spirit is born when an individual is impelled by faith to see the positive things in life and there is a link to divine force. Fowler pinpoints the importance of faith in our lives when he states,

To you I want to affirm the largeness and mystery of faith. So fundamental that none of us can live well for very long without it, so universal that when we move beneath the symbols, rituals and ethical patterns that express it, faith is recognizably the same phenomenon to Christians, Marxists, Hindus and Dinka, yet it is so infinitely varied that each person's faith is unique...Any of us can be illumined in our efforts to relate to the holy by the integrity we find in the faith stances of others, whether they are religious or non religious. (1981:xiii)

Whilst some individuals are unable to view faith in the general terms that have been outlined above, this thesis chooses to see faith as cosmic and universal; faith is all encompassing and is not limited to theology or doctrines. Rather, as Durkheim

explains, 'A faith is warmth, life, enthusiasm, the exaltation of the whole mental life, the raising of the individual above himself' (1965:473). As William James points out,

There must be something solemn, serious, and tender about any attitude which we denominate religious. If glad, it must not grin or snicker; if sad, it must not scream or curse. It is precisely as being solemn experiences that I wish to interest you in religious experiences....The divine shall mean for us only such a primal reality as the individual feels impelled to respond to solemnly and gravely, and neither by a curse or a jest. (1902:38)

Faith then is not represented as a belief that seeks to exclude, or isolate individual members from others. Instead faith opens up the human heart, allowing it to take in the splendour of life, the richness of living. Durkheim, Julian of Norwich, Fowler and James see faith in similar terms. Their writings indicate the experience of faith as being something sacred and all encompassing. Faith, as Elkins (1998:31) puts it, is 'an existential attitude of the heart....It is the proper object of our ultimate concerns, primal truths and searches within'. When a person becomes inspired, when a sense of possibility is awakened within, faith draws near all that is precious, purposeful and meaningful.

Cancer victims who have faith have a resource for coming to terms with illness. Social outlets such as family, friends, professionals, work, seek to assist and maintain the establishment of some kind of faith. This faith may enhance their well-being and self-esteem. Further, as pointed out by research, in the presence of sacred beliefs and religious values, cancer patients are given a sense of support and guidance during their difficult time. Thus, faith, which enables people to view the universe as a friendly and good place, regardless of their surroundings and biological condition, is essential. Transcending the wrenches of our emotions, rising up from the dread of sickness, are the outcomes of a faithful spirit. Viewing the world as a worthwhile place to live in, finding harmony in the day that has begun, result from trusting in and relying upon some greater force.

Having examined the interpretation of faith within the domain of this research, the term '**Global Faith**' will be given to faith that generates a cosmic core-optimism about the world, existence and recovery from breast cancer. Understanding the role of **global faith** in assisting women to cope with breast cancer will be investigated in the course of this research. Having held open a notion of what global faith is, what shapes, sustains and supports global faith, attention will be given to the presence of global faith in women's stories.

### **Conclusion.**

Following the examination of sociological research into breast cancer and coping I have narrowed the aim of this thesis to the role of spirituality and faith in women's experiences with breast cancer. How women in this study are able to exist in a state of harmony with the universe, when a life threatening disease strikes, is the primary concern of this study. How do women in this study discover some meaning in what appears to be senseless suffering? How do they maintain optimism, or a sense that all will be well amidst bodily decay and ruin? In relying upon women's narratives as a means of finding answers to such questions I expect to find some religious faith and spiritual dimensions that will facilitate coping. I will also explore the role of social factors in establishing coping strategies. When listening to women's stories I expect to find reference to themes such as religion, friends and family, work and medical institutions. Further I anticipate that some women will make reference to body image and identity when discussing their journey with breast cancer. Having given little consideration to 'body-image' and 'identity' so far, the next two chapters concentrate on these areas with greater clarity and depth.

## **Chapter Three: Breast Cancer and its Impact on Body Image.**

### **Introduction: The Concept of Body Image.**

*Of all the ways people think of themselves, none is so essentially immediate and central as the image of their own bodies: The body is experienced as a reflection of the self. Body image is the way people perceive themselves and, equally important, the way they think others see them. Body image is constantly changing, continuously modified by biological growth, trauma, or decline; it is significantly influenced and moulded by life circumstances—accentuated by pleasure or pain. (Fallon 1990:80)*

Fallon's (1990) definition of body image takes into account the various ways that people equate their self-worth with their physical appearance. Perceptions of body image, held by men and women, play a major role in initiating and constructing feelings of self-worth and desirability. Physical appearance is often the most readily available information about a person and conveys basic information about that person's gender, race, approximate age and possibly even his or her socio-economic status, or occupation. Further, the style of one's hair, the shape of one's body, the colour of one's skin, are but only a few characteristics which mould people's perceptions of beauty and physical attractiveness. A person's Identity then is closely linked to a sense of satisfaction with one's body and a sense of sexual adequacy amongst relevant peers. Thus, body image is a medium of experience and the instrument of action (Cash and Pruzinsky 1990: 9). If individuals have a positive perception of their physical appearance, then chances are they will view themselves in a more confident light.

Culture greatly affects what becomes the ideal sense of beauty. Culture is seen to set the standard on the formation and maintenance of body image and in doing so

plays a pivotal role in creating measures for what is considered beautiful or ugly, enticing or repelling (Baturka *et al.* 2000). Fallon (1990:80) states that,

Culturally bound and consensually validated definitions of what is desirable and attractive play an important part in the development of body image. One's body image includes his/her perception of the cultural standards and the extent to which he/she matches the standard, and the perception of the relative importance that members of the cultural group and the individual place on that match.

Fallon makes the point that body image is not stable, rather is reflective of and shaped by its environment and the culture to which it belongs. For example, what has been considered beautiful in relation to a woman's figure has varied over time. An increasingly thin standard has emerged for females in our society. Yet, in the nineteenth century, the idealised female was one who displayed "fullness" and the "reproductive figure". One need only view Renoir's *Blonde Bather I* (1881), or Botticelli's *The Birth of Venus* (1485), to see how fat was considered both erotic and fashionable. During these eras artists often portrayed women as plump and voluptuous.<sup>4</sup>

Today, body size is seen as beautiful only if it displays thinness. Social images of obesity for example is highlighted by Cash (1990) as a highly stigmatising condition in our society that can adversely affect the educational and vocational needs of overweight people. Thus, the body shape of a person will determine whether they are liked and accepted by those around them. A thin body is viewed as being attractive. It is seen to represent discipline, control and moderation in one's lifestyle. Obesity on the other hand carries with it a sense of gluttony and disfigurement; obesity

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<sup>4</sup> Such physical characteristics were also reflective of one's class and social status in society. Fallon (1990:95) notes,

A century ago in Western culture a curvy bosomed woman signified luxury. The male's potbelly was worn proudly as a badge of success and well-being, indicating that he could afford to gorge himself on huge meals. When resources are scarce, weight is associated with prosperity and plump women are admired.

In this case body weight is viewed in a variety of ways over time. Culture is responsible for introducing and changing social ideals relating to the perfect body size.

represents excessiveness and loss of control. Yet, an attractive body constantly shifts and is reflective of cultural standards. Cultural standards are based upon values and norms created by social networks.

Social networks play a vital role in establishing codes of acceptance for how a person should look. The media for example is largely responsible for setting trends in fashion and physical beauty. Through commercial outlets, this medium of information sets standards for what is and what isn't considered physically appealing and enticing. Brownmiller (1984) examines the impact of advertisements for commercial skin care on the youth of today. Her analysis makes the point that advertisements and advice columns in women's magazines outline an impossible prescription for maintaining physical beauty (p.131). Brownmiller notes that culture's framework for the image of the human body has disastrous effects on those who fall short of the ideals of sexuality and beauty. She states,

Beauty displayed in magazines is unrealistic and for many teenagers, unattainable. Prerequisites for physical splendour such as clear skin, shiny silky hair, unblemished skin, no bags or shadows under the eyes, no scars or birthmarks, no facial hair or pimples, spell out impractical and nonsensical conditions on what is considered beautiful'. (p.131)

Brownmiller claims that as a result of all these limitations placed upon women there results a difficulty in attaining cultural notions of beauty and desirability,

Appearance, not accomplishment, is the feminine demonstration of desirability and worth. In striving to approach the physical ideal, by corsetry in the old days or by a cottage cheese and celery diet that begins tomorrow, one arms oneself to fight the competitive wars....Because she is forced to concentrate on the minutiae of her bodily parts, a woman is never free of self-consciousness. She is never quite satisfied, and never secure, for desperate, unending absorption in the drive for perfect appearance. (pp. 50-51)

According to Brownmiller, those women who do not fit the perfect ideal of beauty will suffer the consequences of relating to negative body perceptions. Feminine identity and self-concept is at risk when physical beauty does not fit the mould set by cultural standards. Further, freedom to accept the state of one's body, with its scars,

wrinkles, abnormalities and impurities, are taken away when restrictions are placed upon what is considered to be "good" body image. In addition, since self-concept is usually highly dependant upon a woman's satisfaction with her body and sense of sexual adequacy, the imperfections a woman may have, can result in a significant blow to self-esteem. This may in turn result in the development of problems in relationships and social settings.

Breast cancer impacts upon the emotional, physical and psychological states of its victims (Hordern 2000). However, little so far has been written on the inter-relation between the following themes; breast cancer and body image, breast cancer and sexuality and body image and coping (Barri and Mondin 1997; Phelps 1993). This chapter attempts to provide an analysis of the various ways breast cancer impinges on a woman's sense of sexuality. The link between sexuality, self-concept and self-esteem will also be drawn.

### **The Impact of Breast Cancer on Self-Esteem, Sexuality and Body Image.**

Sexuality is a significant source of self-esteem amongst men and women and is one of the most enduring characteristics of self-image. For most people sexuality is related to body image. Any disruption in that image can lead to significant sexual problems. In relation to self-concept and self-esteem, a woman's sexual ability is often based on the degree to which she feels attractive—the size and shape of her breasts can also contribute to the level of attractiveness a woman feels (Gyllenskold 1982; Mead 1949; Zimmerman 1998). Breasts are often viewed as "badges of femininity" (Renneker and Culter 1952) and play a major role in heightening or deflating a woman's sexual ego (Armistead 2000). Breasts also enable women to suckle their young (Goin 1982; Jelliffe and Jelliffe 1977) and can be a source of sexual stimulation (Kaplan 1974; Schoenberg *et al.* 1970). Overall breasts are an essential part of a woman's body image (Meyerowitz 1981; Mock 1993; Wellisch *et*

*et al.* 1985) and contribute to a woman's perception of her femininity and beauty (Langellier and Sullivan 1998; Polivy 1977). Brownmiller (1984:40), defines breasts in the following way,

Breasts are the most pronounced and variable aspect of the female anatomy, and although their function is fundamentally reproductive, they command attention. Breasts are an element of human beauty. Breasts are subject to cancerous lumps. Breasts are a source of female pride and sexual identification, but they are also a source of competition, confusion, insecurity and shame.

Breasts play a significant role in enabling women to feel good about themselves. Firm breasts, voluptuous breasts, are often seen to promote a sexy figure; breasts that draw attention to the male gaze are thus for many women, a source of extreme pride and satisfaction.

Yet, in the event of an illness such as breast cancer, women can be made to feel a great deal of negative and destructive emotions. The breast cancer patient often faces the problem of body mutilation such as the loss of a breast or the infliction of body scars. Consequently, a life threatening illness such as breast cancer can play a huge role in interfering with a woman's sense of vitality, physical attractiveness and sexuality. A central theme apparent in a great proportion of health care literature is that the loss of a breast affects a woman's perception of body image (Cohen 1982; Crouch and McKenzie 2000; Derogatis 1986; Meyerowitz 1981; Mock 1993; Price 1992; Schover 1991). Treatments for breast cancer can damage disfigure or destroy the patient's body organs. Radiotherapy can affect one's sexual desire impairing libido, orgasmic function and vaginal muscle tone (Bourgeois-Law 1999). As well as this, chemotherapy can also cause hair loss, fatigue, hot flushes and nausea (Broeckel *et al.* 1988; Walling 2001). For younger women treated with chemotherapy and radiotherapy there is also the threat of infertility. The chance that treatment can render a woman sterile can lead to high levels of stress and inner turmoil (Smith and Reilly 1994:147).

Women diagnosed with breast cancer are confronted not only with an illness that can lead to death, or infertility, but also disfigurement. Whilst not all women with breast cancer require a mastectomy, many must undergo this type of surgery.<sup>5</sup> A woman unable to tolerate the effects of breast cancer, repulsed by an absence of a breast, can suffer from depression or alienation. Dry skin, menopause, the loss of teeth, feelings of sexual inadequacy, are commonly encountered by women as a result of treatment. Such repercussions of surgery can initiate mood swings and depression. Further, a diagnosis of breast cancer can leave women feeling stigmatised and violated. Vaeth (1980:73) states,

If a person's self-esteem is inevitably threatened by a potentially fatal disease, by painful mutilating and disabling treatment and by the realistic possibility of being alienated from or abandoned by one's spouse or lover, then one is damaged by that disease and its consequences.

It is important to recognise the unique threat that breast cancer carries with it. Vaeth is aware of the social, emotional and psychological implications of breast cancer. He details the impact it can have on women and the extent to which breast cancer can cause women to feel insecure with their partners and those closest to them. Clearly women who rate sex as a central or pivotal aspect in their lives, who suffer the loss or disfigurement of a breast, can view themselves in a negative way. With a damaged perception of self there can emerge insecurities relating to body image and sexual attractiveness.

Glasgow *et al.* (1987) suggest that women most likely to suffer emotionally from mastectomy, finding it difficult to reintegrate their body image following this type of operation, are those for whom the body has a heightened sense of importance. The

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<sup>5</sup> Derogatis (1986) stresses that with breast cancer comes not only the threat of death, but the threat of perceived negativity relating to body image. Further, breast cancer not only destroys healthy cells through its attack on women's breast, but also seeks to endanger a woman's self-esteem, sexual functioning and feminine identity.

stigma associated with the debilitating effects of cancer can leave a woman feeling undesirable and socially isolated. Kolb (1975) believes that society's reaction to disfigurement is one of avoidance, shock and grief. Because of these reactions women tend to confront feelings of humiliation because of their illness. Smith and Reilly (1994:148) detail a case where a woman was made to feel 'contagious' by her friends because of her cancer. As a result of this, the woman withdrew herself completely from her peers, as she did not trust them enough to discuss her illness with them. In these circumstances, when the cancer victim has no-one to turn to, coping with one's illness may be difficult and unbearable. Peters-Golden (1982), reported that of 100 breast cancer patients interviewed, 72% reported that they were treated differently after people knew they had cancer. Of these, 72% found that the most prevalent difference was that they were misunderstood; 52% found that they were avoided or feared; 14% felt pitied, and only 3% thought people were nicer to them than they had previously been. Further, only half the patients interviewed characterised the support they received as adequate to fulfil their emotional needs.

Wortman and Dunkel-Schetter (1979) argue that if cancer patients are given little emotional support during their battle with illness, it is likely that patients will encounter a great deal of distress in their lives. This is especially the case for those women with breast cancer who are treated badly by friends and family and made to feel like lepers and social outcasts. In the event of this occurring, women often feel isolated and rejected from family, friends and society. Wortman and Dunkel-Schetter state,

Since they elicit signs of rejection from virtually everyone, and since the negative feedback is fairly consistent across situations and overtime, patients may draw the conclusions that they are worthless, unlovable and despicable....Ultimately, the self-doubt and isolation which result from disruption of one's social relationships can contribute greatly to the cancer patient's distress. (p.141)

According to Wortman and Dunkel-Schetter, women often feel unloved, unwanted and useless, in the event of cancer. Women, who lack an appropriate social network in which to come to terms with destructive feelings of body image, are likely to suffer severe and long lasting emotional consequences. Wortman and her colleagues have suggested that the opportunity to discuss feelings, particularly negative ones, is an essential form of coping for the cancer patient. Through discussing one's fears and insecurities, greater understanding may be achieved as to how to accept one's altered state of body image. Further, specific stress points felt by women with breast cancer can be highlighted and dealt with when there is an adequate support network to rely on.

### **Conclusion.**

Until now, this chapter has detailed little on global faith and its relationship to body image. The reason for this is that I felt it necessary to firstly examine the impact of breast cancer on self-perception, self-esteem and self-concept. In examining such aspects I am led to question the role of global faith in facilitating acceptance of an altered body? Does global faith help the women in this research to come to terms with feelings of shame and humiliation that are tied to an imperfect body image? Can global faith provide a sense of support for those women who are shunned away from friends and family? Yet, before I can set about seeking explanations to such questions it is imperative that I firstly explore the concept of identity. The next chapter seeks to investigate the role of identity in the lives of women with breast cancer.

## **Chapter Four: The Role of Identity in the Lives of Women with Breast Cancer: A Post-Modern Investigation.**

### **Introduction.**

*A woman's definition of self is based on a lifetime of feedback about having breasts, menstruating and being able to engage comfortably in sexual activity. Breast cancer threatens this self-perception. (Chamberlain 2001)*

When investigating body image and the impact of breast cancer on women's perceptions of 'self' and 'physical appearance', it is important to consider the role of identity in women's lives. Identity and a person's social role are entwined within a fabric of worldly expectations, meanings and values. When secular views on appearance and behaviour are not met, then an individual can feel isolated and not in control of his or her life. In the event of a serious illness such as breast cancer, a woman's sense of identity can be severely challenged. A loss of a breast, sickness, an inability to wear sexy clothing, an absence of hair, can all impinge upon a woman's sense of identity. Sexual identity, gender identity, cultural identity and feminine identity, can be altered when a woman perceives herself as deformed and mutilated. Further, identity roles such as the mother, the lover, the worker, or the friend, can be threatened with the onset of cancer. This in turn can lead to problems with coping and adjusting to illness. It is therefore essential to examine identity in women's lives if we are to understand how women cope with breast cancer. This chapter begins with a definition of the term identity. Following this I outline how cultural meanings and ideals shape the identity of women living with breast cancer. Understanding how identity is manipulated and formed by capitalism and the modern world is also given some consideration.

### **What is meant by identity?**

Cultural ideals, images and metaphors provide frameworks within which we define ourselves and find meanings. Social networks such as religion, school, family, and gender also dictate our place in the social scheme of things. Ethnicity too, embeds a seed of culture within us that has a habit of rooting itself into our mode of existence. The gestures we make when communicating with others, the cultural food we consume, the religious and social rituals we partake in, are quite often the result of a person's heritage and history. Thus, identity is an important aspect in the lives of all of us. Woodward (1997:2) states, 'identities are produced, consumed and regulated within culture, creating meanings through symbolic systems of representation about the identity positions we might adopt'.

Our sense of place in the world, our narratives, our views of life and living are all intertwined. What emerges as a result of this, are culturally shared beliefs, commitments and expectations that define and sketch out who we are. How we interact with others and the boundaries that are drawn in our dealings with certain social groups, are also grounded in the identities we attach ourselves to. There are various identities that an individual may take on in his or her lifetime. Like a collage, the social construction of identities comes in differing shapes and sizes—identity has a variety of textures and is made up of differing colours and fabrics that create an overall impression of the social being. Thus, the athlete, the student, the religious preacher and the child, are but a few social roles that can be adopted by individuals during their lifetime. Taking on certain identities provides individuals with a fundamental feeling of belonging and unity. Individuals gain strength by connecting and identifying themselves to a certain group, or status. Shared ideals and values help to collect and bind the individual to a greater force (Durkheim 1965). Identity

therefore plays an important role in the way people communicate and respond to others. Jenkins (1966:20) claims,

If identity is a necessary prerequisite for social life, the reverse is also true. Individual identity—embodied in selfhood—is not meaningful in isolation from the social world of other people. Individuals are unique and variable, but selfhood is thoroughly socially constructed: in the process of primary and subsequent socialisation, and in the on going process of social interaction within which individuals define and redefine themselves and others throughout their lives.

Being able to link with others who share a similar role can therefore promote a sense of stability in a person's life. The degree to which people feel powerful can be tied to their perceived identity. The person, whose identity is tarnished or damaged, can face feelings of powerlessness and dread. The foreigner, the new student, the sick patient and the invalid can find it difficult to assert control over their lives when their identity is questioned by outside forces.

Culture is the spinning wheel that seeks to shape the social roles we place ourselves into. According to Bruner (1990) we are firmly rooted in a historical context that highlights the necessary framework from which meanings and identities are constructed. Bruner writes,

The symbolic systems that individuals used in constructing meaning were already in place, already 'there' deeply entrenched in culture and language. They constituted a very special kind of communal tool kit whose tools, once used, make the user a reflection of the community. (p.11)

Culture plays a central rôle in shaping and moulding who we are and how we might come to view ourselves. Further, culture provides us with a shared symbolic system of rules essential for constructing meaning and dealing with difference. Through the establishment of cultural movements that create a value system to which we look to, identities are manipulated and at times fragmented. Personal, philosophical, political and social aspects in our lives are governed by culture. Culture is dependant upon a number of sources that attempt to sculpture, tame, and dictate the construction of a

person's identity. Sarup asserts, 'our identities are influenced, among other things by what we consume, what we wear, the commodities we buy, what we see and read' (1996:105). Our identities are thus formed, carved and forged by the cultural influences in our lives. The shaping of identity through cultural influences enables individuals to construct their own thoughts and establish representations related to self, others and the external environment.

Identities are founded on the social make-up of discourse. The way in which we use language to communicate to others and convey meaning is also dependant upon identity. The culture we belong to, the social class we align with, will ultimately dictate the stories we tell, the legends passed on, all of which contribute to the formulation of identity (Taylor 1989). Through the unfolding and developing of narrative configurations, we are able to learn about ourselves, our past and future. Thus it is essential to 'organise human life into temporally meaningful episodes' (Polkinghorne 1988:1), that delineate what is important in everyday affairs. In doing so we are better able to grasp the sacred things that shape the world we live in. Hence, language in itself is geared towards labelling human beings into specific categories of experience, providing the necessary matrix from which meanings and social roles are constructed (Bruner 1990).

Cline (1996), like Sontag (1978), examines the role of language in the lives of the sick and dying. According to Cline language is largely responsible for the way in which we view the sick person; language provides the framework for how death and dying should be viewed. Cline (1996:37) states,

Language is one element that helps to construct our modern taboo around death. It is not a neutral means of communication. It transmits attitudes, values, and models of behaviour. It sets the tone and decrees the ground rules. Language either conceals through suppression what is significant about death from natural causes, or through its highly coloured inflammatory metaphors, it stigmatises certain diseases and victims thus intensifying the spiritual disquiet which might be expected to come with human awareness of mortality.

If there is no language to delineate the importance and significance of death in our lives, if language serves as a barricade for expressing ideas and views on dying, then identity is affected. In the absence of words that attempt to find meaning in illness, identity and one's spirit will most likely suffer and become disenchanted. When a culture fails to provide its people with a means of communicating feelings, individual lives can become easily detached from their world (Charmaz 1995). When identities are challenged, or threatened, people can feel worthless and unappreciated.

Although identity for some people can be a source of immense pride and happiness, it can be for others an emblem of extreme pain and suffering. Whether we feel wanted, or rejected will reflect upon the validation we receive by those we have dealings with. Feelings of comfort and satisfaction with regard to one's identity are also closely linked to an individual's perception of self. When we look in the mirror and see a beautiful reflection staring back, we distinguish the traits needed to define limits of physical attractiveness. Physical characteristics pinpointed as beautiful and ugly are culturally acquired. Most importantly though, whatever we become, or wish to be, can be the result of the identity we feel best represents our inner perceptions. According to Weeks (1990:88), 'identity is about belonging, about what you have in common with some people and what differentiates you from others. At its most basic it gives you a sense of personal location, the stable core to your individuality'. When individuals are unable to attain this sense of belonging, then feelings of rejection and loneliness may be encountered. Each one of us needs to feel that we are a part of something or someone; we all want to feel loved and appreciated by the various forces that dominate our lives. Identity is therefore a key element that enables a person to develop not only a sense of importance, but also a link to others. When a

certain identity is shattered, then overwhelming emotions can take over a person's outlook on life and a desire for living.

When culture fails to communicate its ideals in ways that can be inwardly viable to each and every one of us, human identities can be transformed into an anchor that has nowhere to lodge itself. In the advent of high modernity, we have seen an obsession with the body that has become for many the main focus for expressions of self-identity. From a young age we are influenced by the television programmes we watch. Popular cultural icons bombard us with set precedents for how our body should look and feel. Turner (1984) highlights the role of the body in modern society. He sees the body as a modern construction and a modern project. Turner argues that the body's appearance, size and shape is heavily monitored and controlled in contemporary society. Such regulations placed on what the body should look like 'involve a practical recognition of the significance of bodies; both as personal resources and as social symbols which give off messages about a person's self-identity. In this context, bodies become malleable entities, which can be shaped and honed by the vigilance and hard work of their owners' (p.5). Turner also investigates the detail given to the personal construction of healthy bodies, bodies devoid of fat, cholesterol and disease. Society propels the belief that diseases such as cancer, diabetes, heart attacks and strokes, are seen to be avoidable if people take care of their bodies. Anti-smoking advertisements inform the public of the risks of cancer and dietitians frequent our newspapers warning readers of the dangers of unhealthy eating patterns. Hence, individual responsibility for healthy bodies is depicted as the key element to preventing a sick body. Such outlooks to health create unrealistic expectations on the nature of the body whereby individuals see their bodies as fortresses that can be shielded from inescapable risks (Beck 1992).

Teenage magazines such as *Cleo*, and *Dolly* seek to educate female adolescents on the ideal weight they must be in order to be viewed as beautiful and pretty. Standards are set and limits are drawn on how much young girls must weigh if they wish to be seen in an attractive way. Attraction often leads to acceptance by others. Adolescents who attempt to identify themselves with models in magazines can find themselves fighting an endless battle. It is not long before the adolescent has an identity crisis and with the onset of acne, weight and hormonal changes, depression and despair can soon set in. The media and other social networks play a powerful role in setting limits on aesthetic beauty. Woodward (1997:65) writes,

Images of the 'body beautiful' circulate within advertising and consumer culture at an ever-greater rate, while many people spend large amounts of time and money attempting to change the shape and appearance of their physical selves. Newspapers, magazines and television programmes bulge with features on body image, plastic surgery, and how to keep the body looking slim and sexy, while weight loss and keep-fit centres have become multi-million dollar industries.

Hence attaching a monetary value to body shape has provided individuals with a means of self-expression and a way of feeling potentially good, or bad about themselves.

### **How Cultural ideals influence the identity of Women with Breast Cancer.**

It is unfortunate that those who do not measure up to the ideals of physical beauty will often suffer from low self-esteem and shame. In the case of women with breast cancer, mastectomy and illness can 'undermine the unity between body and self' (Schain 1980). Women, whose breasts are maimed, whose genital organs are cut off, as in the case of a hysterectomy, may view their sexuality in a negative way. Writers such as Charmaz (1991) and Murphy (1987) believe that feminine identity will more than likely suffer when chronic illness brings on impairment. As in the case of breast cancer, the removal of the breast can lead to the castration of a sense of wholeness of body and self. Further, when

messages are sent to women that a healthy body is dependent upon self-care, women with breast cancer may feel responsible for their illness. Further, public images that portray the body as being free from disease and sickness as a result of diet and attitudes, can lead women with breast cancer to also blame themselves for the style of living they have previously lived. No doubt women who are faced with such feelings will ultimately feel inferior to the ideals of beauty and sexuality that are placed before them. As Kestenbaum (1982) observes, a person's sense of self-respect is seriously threatened in the event of a chronic illness. Impaired bodies, as in the case of women who have had a mastectomy of either one, or both breasts, can lead them to view themselves in destructive and negative ways. Further, integrity becomes tarnished when it is compared with the labels modern society places on the ideal body, as 'meanings of loss are embedded in assumptions and discourses about the body', (Charmaz 1995:660). The woman who has only one breast, who is sterile and suffers from early menopause, may also face becoming socially identified as being imperfect and labelled accordingly.

It is no wonder then that many women with breast cancer suffer because of the way they are treated by others. Negative experiences of breast cancer, more often than not, prevent women from taking part in normal social activities. When their identities are tied up with motherhood, work, relationships and sport, illness can weaken, or immobilise their performances. The majority of women with breast cancer, in the throes of chemotherapy and radiotherapy, are no longer able to make their children's lunches, meet with their friends for social occasions, and even go to the football to see their favourite team play. Corbin and Strauss (1988:357) explain,

When people are unable to complete actions enabling them to carry out tasks associated with various aspects of the self (Whether this is an inability to perform as a teacher, or normal "father" or even to carry out the activities of daily living), then certain aspects of the self become "lost". Since the integration of these various aspects of the self forms the more inclusive self, or identity, with that loss comes an accompanying sense of loss of wholeness.

Shame and humiliation can soon set in when there is a breakdown, or malfunctioning of the human body. Women who are unable to carry on with normal everyday activities can

feel let down and useless; women faced with the prospect of death can discover new depths of loneliness and depression. Thereinafter, identities can be transformed from personifying an active, strong and focused view of life to a fragile, and volatile perception of existence. (Kidel and Rowe-Leete 1988). Yet, if we take into consideration Berger's point that 'death is an essential feature of the human condition that requires people to develop means of coping with it, to neglect death is to ignore one of the few universal parameters in which social and individual life are constructed' (Mellor and Shilling 1993:411), perhaps many women with breast cancer would not be faced with an identity crisis. If women with breast cancer were taught to view their physical state and their social condition in more of a positive way, then unhappiness and instability could perhaps be avoided.

Breast cancer largely affects social identifications and self-definitions that women place before them (Charmaz 1995). For this reason it is important to investigate the impact of breast cancer on self-identity. In order to understand the various ways in which a chronic illness, such as cancer, can influence the discernment women have about their identities, we must listen to their stories. Through their biographies light can be shed on their dealings with facing ongoing experiences (Bury 1982; Corbin and Strauss 1987; Radley and Green 1989). The narratives of women with breast cancer are essential when examining how women cope with illness. Their stories are also valuable in detecting those sources they draw upon as a means of coming to terms with identities that have become distorted and damaged. Narratives in this research will be used as a means for highlighting tools used by women in coming to terms with, accepting and re-evaluating a shattered sense of self-identity. Chapter seven highlights the stories of twenty women and their battles with breast cancer.

Charmaz (1995) examines the notion of adaptation to illness and sees 'acceptance' as being a key tool in regaining a sense of composure in the advent of a dysfunctional state of body image. She states,

By adapting, I mean altering life and self to accommodate physical losses and to reunify the body and self accordingly. Adaptation implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways. Body limits and social circumstances often force adapting to loss, adapting shades into acceptance. Thus, ill people adapt when they try to accommodate and flow with the experience of illness. (p.648)

Chamberlain (2001) also sees acceptance as playing a pivotal role in women's life experiences and their resolutions to illness. Once a woman accepts her new look, she is better able to deal with disease and does not need to hide the reality of illness. Only then can a lifestyle be seen to be worthwhile and productive. She writes,

Patients in whom breast cancer is newly diagnosed also must accommodate to changes in their physical appearance, changes in their monthly menstrual cycle or its loss, and changes in the way they respond to sexual stimulation. The taking in of these losses is critical before they move to the next stage of adjustment, that of taking hold and making meaning of this experience. Acceptance of and taking on an altered sexual self-identity appears to occur once they have made some meaning of this diagnosis and the changes in their sexuality caused by treatment. This is consistent with the concept of self-transcendence, and may reflect another dimension of the growth that often comes from a crisis. (p.285)

Self-identity and sexuality is reshaped and its boundaries redefined when a person attempts to transcend stigmas and negative labels that are placed on the sick body. When this occurs, victims of disease are able to view themselves as much more than their body and illness. In the process of achieving a sense of acceptance in a life journey that is fought with illness, women's attitudes of self can bring forth fresh and enlightening ways of living and feeling.

### **Capitalism and Identity.**

The secularised world we live in shapes our identity. According to Castells (1997:1), 'The information technology revolution and the restructuring of capitalism have induced a new form of society, the network society'. With our technological advancements, the modern world is bent on achieving calculable ends whereby scientific discourse replaces 'God' with 'humanity' and humanism becomes the centre of our universe (Lyon 1994). Thus, in high modernity there is the destruction of 'sacred' forces in our lives whereby that which cannot be touched or poked, is

deemed insignificant. 'In modern society the growth of positivistic scientific and technological knowledge systems inflates the importance of knowledge as a basis for action almost to the level of sanctification. Such forms of knowledge displace religious knowledge systems and in doing so demystify the world' (Crook *et al.* 1992).

When knowledge prides itself on that which can be quantified and manipulated, freedom of expression becomes lost in a sea of compulsion and regulation. Social networks that seek to disempower individuals from expressing their deep-seated emotions thus fabricate identities in the modern world. Carroll (1998) has spent many years examining this very theme. His writing suggests that contemporary society is lost in the realm of computers; society is founded upon systematic answers which have in turn led to a loss of meaning and the destruction of a real sense of sacredness in human lives. Whilst Carroll views modernity's plight as being somewhat humanistic, he nonetheless looks for evidence of the sacred resurfacing amidst a plethora of robots and mechanics. In Carroll's (1998:187) words,

As the churches have emptied in the West it has been in nature that most have sought the divine. Going to the country, picnicking by a river, fishing, walking in the forests, bicycling, camping in the bush, climbing in the mountains, skiing, boating in the lakes, sitting on the beaches, standing on cliff tops, gazing out over the oceans, even favouring life in suburbia where each home has its own back-garden, so many modern ways of retreat have been found from the metropolis, in search of some peace and serenity, some inspiration, some release from self into union with the All.

Such an analysis of the ways, in which the modern individual finds or discovers a sacred pathway to an inner source, is essential for this study. The reason being some women with breast cancer may find it difficult to attach themselves to a divine force that is constructed from a paradigm of science and reason. Simple things in life may therefore offer these women a sense of peace from suffering. In the event of contracting an illness, women will often take pleasure in and sanctify things that cannot be purchased over a counter, or fabricated from a technical hand.

Lyon (1994; 1999), like Castells, also examines the progressive rationalisation of life and the impact of capitalism on identity. In a society where industry and economic rationalism are paramount to the modern world, progress becomes central to existence. Identity takes on a different form amidst calculating attitudes and lifestyles ruled by the constant pursuit of profit and capital. Capitalism therefore plays a major part in the construction of identities; capitalism has led to a Western culture obsessed with the acquisition of materialistic gain and financial success. Human happiness in the process is equated with a person's market value. Contentment and human direction becomes a commodity in itself and life experiences and social identities can be attained through a credit card, or an email address. Lyon is aware of the pliable and changeable nature of the modern identity. At the blink of an eyelid and presuming a person has money, he or she can buy an image and a persona.

And on a personal level, identities are constructed through consuming. Forget the idea that who we are is "given" (by God) or achieved (through hard work in a calling or a career); we shape our malleable image by what we buy—our clothing, our kitchens and our cars tell the story of who we are (becoming). It is no accident that the world of fashion is seen as an 'identity industry', the idea that our self-esteem and our recognition by others, may be purchased over the counter. (1999:17)

According to Lyon, identities are easily bought and managed. The social class we belong to, the school we send our children to, the travel destination chosen for a family vacation, the suburb we live in, are determined by the buying power we have. People's self worth, their success and value, are represented by their wealth and income. Hence, in a world of mobile phones, computer programmes, satellite T.V and cosmetic surgery, technology and the scientific realm seek merely to control and manipulate. When consumption becomes a mode of being, or a pathway to prestige and importance in contemporary society, buying power can be a controlling force in people's lives.

Women, who inherit a sick identity, may find it difficult to conquer negative perceptions of self through their buying power. All our lives we have been taught that anything can be achieved, all is permitted when money is available. In the advent of cancer, cosmetic surgery provides escapism from deformed breasts, wigs allow for the illusion of healthy vibrant hair. But, what of the sick soul? What is it that can be bought to mend a broken heart and a damaged perception of self? Where is society's emotional prosthesis that can latch itself to a woman's psychological state, to her inside heart so that she may walk erect and be not weighed down by the misconceptions placed on the diseased body? Global faith must surface here. It is my hypothesis that global faith provides transcendence from modernity's inability to face death; modernity has difficulty accepting that which it cannot control and tame. The cancerous cell, ravenous in its initial stages of growth, pubescent in its take over of healthy cells, is no match for the world that seeks command and authority over all things. A trust in a higher power can offer women a sense of control within. Despite the often uncontrollable workings of a diseased body, thoughts and actions can be influenced when hope is placed in a sacred force; a belief in the transcendent force can assure women that it is safe to move forward, even if their future is uncertain. Yet, there are some theorists who argue that the sacred cannot be found in modern life. This next section closely examines the writings of certain academics who see disenchanted and alienated individuals as having emerged from an over secularised world.

### **Marx, Weber and Disenchantment.**

Theorists such as Marx view capitalism as being responsible for altering the identities of people. The Marxist view holds the process of commodification and its craft, the capitalist mode of production, to be largely responsible for society's discontents. Under modes of production, identities of the modern wage earner take on a meaningless form whereby the worker becomes estranged from nature and his or her

own physical body (Mandel and Novack 1971). Work, according to Marx, is no longer a means of self-expression, where the labourer is responsible for the entire making of a product. Take for instance the Italian carpenter, who takes the time to carefully craft his table and chairs; more often than not a sense of pride is felt when the task is finished. Or, think about the makers of Ferrari, who handcraft automobiles, beginning from start to finish. Indeed both these workers encounter a sense of great accomplishment upon the completion of their work. A feeling of satisfaction can also be tied to the identity of the worker who perceives work as being founded upon principles of self-expression and creativity.

The identity of the factory worker however is viewed by Marx in a critical way because, 'the modern wage earner owns none of the products of his own labour, under capitalism not only does the wage earner lose possession of the product of his labour, but these products can function in a hostile and infurious manner against him' (Mandel and Novack 1971:22). Outlined in his political manuscript *Capital* (1928) Marx looks to the production of commodities as having a destructive influence on the assembly line worker. He believes that in the production of capitalistic goods, the assembly line worker transforms into 'a living appendage of the machine' (1928:484). Having no control over the product that is made and what becomes of it afterwards, Marx identifies the worker as being alienated.<sup>6</sup> According to Marx, people are alienated from their source of production because they do not own their means of production. When work itself is not creative and tasks of work enforced upon labourers are repetitive and unrewarding, the worker experiences dissatisfaction with his or working environment (Mandel and Novack 1971:62).

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<sup>6</sup> Marx's uses the term 'alienation', to refer to any state of human existence whereby the individual is 'separated by', 'external' to his/her work and way of life.

In working on assembly lines, where work becomes fragmented and simplified, it is difficult for men and women to feel connected to their work. As a consequence the workers' relationship to their productive activity and their co-workers becomes 'estranged' and 'meaningless'. Thus Marx's theory of alienation pinpoints the damaging effects of capitalistic production on human beings, where the worker 'does not develop freely his physical and spiritual energy but mortifies, his body and ruins his mind' (*ibid.*). Consequently, the limitation of independent thought in certain fields of work, the estrangement of special traits and abilities inherent within economic pursuits, contribute to the destruction of the worker's physical and mental state. Capitalism restricts human freedom and autonomy. According to Marx, the destructive nature of capitalism is that it is morally disabling, hindering individuals from leading meaningful and constructive lives. Hence, Marx is concerned with the human condition under capitalism and views capitalistic endeavours as being responsible for altering the spiritual minds of people.

The notion of disenchantment, as a result of rationalisation, is examined by Weber (1958). Whilst Weber does not write on dying and illness in this text, he does detail the impact of rationalistic endeavours on the human spirit. According to Weber the human spirit is unable to believe in anything unconditionally in the presence of an over secularised world. As a result of this, faith and spirituality in the modern world have taken on a new meaning. Weber's theory not only explores the emergence of Western culture through the historical inter-relation of religious ideas and economic movements, but also probes the futuristic dilemmas that await the 'spirit' of humankind. Absolutely central to Weber's thinking is the frightening social and cultural consequences that emerge within the liberal societies of the West. He links capitalistic pursuits and rational modes of behaviour to the destruction of a belief in mysticism and the transcendent. In his analysis of the decline of Western culture, he also questions how a seedbed of a trend now enveloping the world, has come to

dominate not only the temporal course of everyday affairs, but also the space of thought, the realm of action (Giddens 1971). Such questioning provides a valuable insight into the reasoning behind a world overwrought with social constructs of instrumental orientations and a culture's obsession with rational and scientific modes of expression.

In his critique of knowledge and power, Weber expounds the belief that with the introduction of capitalism, there has evolved a whole series of relations, which have worked powerfully against the spontaneous enjoyment of life. With a secularised world where all is predictable, where the primal concern is for material gains and scientific discoveries, there precedes a culture dominated by the making of money. Weber sees the desire for material advantages, as only destructive to the individual and his/her social relationships. Similarly, Dostoyevsky's main character portrayed in his novel *The Underground Man* (1972:122), shares this view of modern culture,

We are so unused to living that we often feel something like loathing for 'real life' and so cannot bear to be reminded of it. We have really gone so far as to think of 'real life' as toil, almost as servitude, and we are all agreed, for our part, that it is better in books. And what is it we sometimes scratch about for, what do we cry for, what do we beg for? We don't know ourselves.

Both Dostoyevsky and Weber make it clear that in humankind's attempt to compel a methodical form of existence and culture, people become disillusioned and pessimistically inclined.<sup>7</sup>

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<sup>7</sup> To clarify these ideas it is essential that we examine Weber's beliefs on the components necessary to perpetuate a 'spirit of capitalism' in modern society. Such a definition is essential, if any understanding of its dynamics within a civilisation is to be seen. Weber, preoccupied with the dissolution of the traditional European culture and society under the impact of industrialisation, identifies two key features in his attempts to pinpoint the 'spirit' of capitalism. Rationality is the first principle. Weber outlines that, with the introduction of rational innovations into the work force there resulted a transformation in labour power and social relations. In the case of farmers for instance, the introduction of the tractor and high-powered forms of machinery meant an increase in their production of goods. With the introduction of such technical devices there resulted a shift in the areas of work carried out by labourers. Skilled hands were no longer required to plough and harvest crops, but were instead needed for the controlling and manufacturing of machines. Similarly, the introduction of piece-rates in agriculture is also another rational innovation that, 'the modern employer uses in order to secure the greatest possible amount of work for his men' (1958:59). A system of piece-rates meant that workers were paid according to the intensity of their work alongside the time taken to complete a task. In both these cases, rationalisation is seen as a fundamental element in dictating the lives of workers. The rational approach ensures that labour is systemised as the only consideration.

Weber's primary concern in *The Protestant Ethic and the Spirit of Capitalism* seeks not only to explain the historical roots of capitalism in Western civilisation, but also

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Weber also concentrates on the Protestant's obsession to work as a means of explaining how it was that they became rich and powerful. In the presence of such an ethic, labourers set about performing work tasks to the best of their abilities. In aiming towards reaching one's fullest potential in industry, workers stayed longer than was required of their services, leaving less time to be spent with families and leisurely interests. As a direct result of this their lives became monotonous, mundane and always predictable. Weber questions the rationality of such an ethic, where 'money making as an end in itself to which people were bound, as a calling, was contrary to the ethical feelings of whole epochs' (1958:73).

When questioning how it was that this spirit of capitalism came to surface in Western culture, when examining where it was that this seed was nurtured and nourished, Weber looks to the decline of the Protestant Ethic. Furthermore, his investigations on the relationship between the old Protestant ethic and the spirit of capitalism direct him to the Reformation and the father of Protestantism, John Calvin (1509-64). Calvin's doctrines as outlined by Weber, are significant to understanding why it was that work and the making of money were transformed into a 'sacred' entity. Weber begins with the notion of predestination and salvation, as defined by Calvin in Protestantism. It was Calvin who brought forth the belief that God determines one's fate in advance, that 'By the decree of God, for the manifestation of His glory, some men and angels are predestined unto everlasting life, and others foreordained to everlasting death' (1958:100). According to Calvin's doctrines, since God is all-powerful he knows everything; God commands the past, the future and everything that is to be. The fact that God has already preordained that some few had been chosen to be saved meant that no-one could buy his or her way into heaven. Thus religious rituals such as confession, mass, penance and prayers would be of no use to the saving of human souls. No longer could people work off their sins with ten 'Hail Maries' and a donation of money to the poor, for their passage way into heaven or hell was dependent upon the sheer mercy of God.

Weber argued that this notion of predestination created a great deal of anxiety amongst the Calvinist believer. Followers fearful of facing hell upon their deathbed, were led to question who the chosen would be? How would they know that, at the moment of death, when faced with the termination of their human existence, everlasting life would be theirs? To answer such questions, Calvin derived the idea of 'Vocation'. Men and Women were forced to look into their hearts to create their own salvation. The means by which this grace from God could be found was in their work. Only in an incessantly active life, through the medium of work, would the Protestant measure up to the idea of religious piety. Measureless labour and hard work was thus seen to be the only path through which one could live up to the idea of grace and purity. The God of Calvinism demanded of his believers 'not single good works, but a life of good works combined with a unified system' (1958:117).

Vermeer's painting *The Lace Maker*, illustrated in appendix 4.1, represents vocation. It is a painting epitomising domestic content and industry. The subject of the picture personifies the very essence of the word "vocation". The Lace maker finds solace in her work and lives but for her needlework. Amidst the carefully placed objects that surround her, the brightly coloured rug, the book of knowledge, the lace maker concentrates only on the task before her. All that brings meaning to her life is the devoted work of her hands and her technical accuracy.

The isolation of the lace maker is surely seen, her desolation surely felt, for it is her work which remains her constant focus. Her loneliness is sublimated to her vocation and her work justifies any inner pain. This is Calvinism at its best; where humans are forced to triumph over their religious anxieties via the medium of labour, and hope that they will be justly rewarded in the process. The woman in the painting is the product of Protestantism and the portrait demonstrates the consequences of salvation being connected to life long work. Her facial expressions show how unnatural and painful this life of strict rule and discipline can be for ordinary people. Rationality, without any balancing of emotional needs leads to inadequate human development. Vermeer's focus on 'indoor-scapes' further emphasises the way in which the work ethic separated people from nature.

Work being transformed into a 'holy' entity, motivated Puritans to go into business. The notions of predestination and vocation ensured that religion penetrated life deeply. Their work therefore became an expression of faith; it is what gave their life purpose and meaning. Thus many hours were spent at work where one could dedicate time and effort into being 'saved'. In the process Puritans became extremely rich and their businesses flourished. Their emphasis on dedication to work helped make Protestants money and become wealthy.

the spiritual displacement which emerged as a result of a rational mode of being.<sup>8</sup> According to Weber, within a secularised world where all is predictable, where the primal concern is for material gains and scientific discoveries, there develops a society devoid of meaning and purpose. When routine and system become the very essence of existence, when salvation is only answerable to limits and intellectual systematisation, there prevails an inability to believe in anything without limits. With the annihilation of unconditional beliefs and the destruction of the sacred, culture transforms itself into a meaningless, futile civilisation. Dawson (1950:11) also holds a similar view of the impact of modernity on the human spirit when he states,

The whole tendency of modern life is toward scientific planning and organisation, central control, standardization and specialisation. The nearer modern society comes to a state of total organization, the more difficult it is to find any place for spiritual freedom and personal responsibility.

Weber saw a sacred force as being difficult to attain in a world obsessed with science and technology. In the Protestants' desire to acquire as much capital as possible and concentrate on the attainment of wealth and power, their religious beliefs underwent a rapid transformation. Once work and prayer were inseparable, but with the spread of capitalistic endeavours work began to take on a whole new meaning. With the success of business and capitalistic endeavours, the 'spirit of capitalism' took on a life of its own and no longer depended upon religion for guidance. This can be clearly seen when Weber says,

The people of capitalism today tend to be indifferent, if not hostile to the church. The thought of the pious boredom of paradise has little attraction for their active natures; religion appears to them as a means of drawing people away from labour in this world. (1958:70)

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<sup>8</sup> The distinction between formal and substantive rationality is fundamental to Weber's social thought, linking his empirical analysis of modern society with his moral response to it. The rationality that Weber concerns himself with in modern society and in the Puritan ethic is vocation. In underpinning the modern rationality of social order, Weber draws our attention to social systems needed to promote a calculated form of existence. Capitalism, technology, and science are areas that are highly rational in their framework. It is the tensions which arise from these institutions that find their way to his prognosis of substantive rationality which is defined as being the values, belief or meaning placed on ends or results (Dawson 1950).

In the event of Protestants concentrating purely on money as a means of fulfilling their lives, business is no longer tied to the sacred. All that remains is rationality, whereby meaning becomes controlled and limited. According to Weber, when this occurs, 'disenchantment' soon sets in, where the lives of individuals revolve around an axis of shift work and mechanical objects. Machines and scientific discoveries become a source of comfort, and life becomes serious, lacking any spontaneity. In having no religious order to underpin one's salvation, in the destruction of mysticism and a divine force, the attempt to justify life-activity is reduced to 'worldly' passions. Material gratification, a desire to reach all limitations thereafter becomes central to the driving force of capitalism.

In a world built upon rules and regulations, Weber believes life becomes intolerable. With the prosperity of capitalism, all that remains is a life founded upon order and rigidity. This is the price paid with the disillusionment of a higher order. Modern society is thus imprisoned within an existence of limitations; modern society takes on a rigid framework that resembles an 'iron cage'. Within this cage, Weber asserts that the everyday affairs of humankind have become trapped inside an embodiment of rules and regulations; freedom for the individual ceases to be. This reality is like the gloomy forebodings of Nietzsche's character Zarathustra, when he announced to his people, "Alas, the time is coming when man will no longer shoot the arrow of his longing beyond man, and the string of his bow will have forgotten how to whirl!" (Nietzsche 1976:129). Weber, too, foresaw something very similar to the total victory of the 'technical worker' over the 'cultured individual'. Weber foresaw the future as belonging to the industrial professional, willing to lead a life of technological innovation, willing to discover all that is. This left little place for cultured and creative individuals whose spiritual ideals kept them alive. Weber was not entirely sure about our freedom in the future,

No one knows who will live in this cage in the future, or whether at the end of this tremendous development entirely new prophets will arise, or there will be a great rebirth of old ideas and ideals, or if neither, mechanized petrification, embellished with a sort of convulsive self importance. For of the last stage of this cultural development, it might well be truly said: Specialists without spirit, sensualists without heart; this nullity imagines that it has attained a level of civilisation never before achieved. (1958:182)

Freud (1963), like Weber and Marx, believed the progress of modern society would prove a destructive element on the freedom of humankind. He recognised the ultimate irrationality of technological reason. He too saw the growth of rational action as an elementary feature in modern society and a contributing factor to the discontents of its people. Whilst Weber chose to describe his futuristic prophecies of the modern world with the symbolic fragmentation of an 'iron cage', Freud saw a world in which scientific and technological progress resulted in the extreme repression of individuals. Further, he believed that this focus on science and technology would lead to a society bound up with an increased number of anxieties in the form of 'neurotic' disorders.<sup>9</sup> Freud therefore provides another dimension to Weber's 'disenchanted' world and even Marx's alienated worker. Freud maintains that civilisation, through technological and mechanical advancements and its endeavours to excessively control and manipulate all spheres of life, has brought forth nothing but pain and misery upon the human condition.<sup>10</sup> It should be stated however that according to Freud, repression in the form of cultural restraints was essential for regulating human instincts. Freud points out that human instincts are destructive in their very nature setting no limits in their pursuit of pleasure; human instincts will overstep all boundaries in their desire for preservation and are 'capable of every sort of sadism and violence, perversion and transgression against order'

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<sup>9</sup> Neurosis is defined by Freud as, 'the outcome of a struggle between the interest of self-preservation and the demands of the libido, a struggle in which the ego had been victorious but at the price of severe sufferings and renunciations' (1963:55)

<sup>10</sup> Freud, unlike Weber, acknowledges the inestimable value of modern technology in lengthening the lives of human beings and protecting them from two sources of human nature being the power of nature and the weakness of our bodily functions. Freud maintains that modern progress in both these fields has come at a great cost to humankind. As a consequence to this he states that the whole effort of civilisation 'is not worth

(Abramson 1984:9). Consequently the survival and progression of civilisation is dependant upon its 'control' over these instinctual forces. Only in 'taming' and 'limiting' the level of gratification obtained by humankind's innate desires, can civilisation have the strength to rule and conquer. Yet when this 'taming' becomes excessive, which can quite often be the outcome of scientific and technological progress, there emerges extreme forms of repression that can generate human anxieties.

Freud's attempts to examine the tragic opposition between scientific, rational progress and human nature can be clearly seen in his text *Civilisation and Its Discontents* (1963). Freud traces the 'discontents' of humankind to the extreme forms of 'repression' which accompany certain types of cultural pursuits and activities.<sup>11</sup> While Freud views the repression of humankind's innate desires as being essential to the workings of a civilised society, he sees excessive 'repression' as being destructive to the personality of the individual. According to Freud, when there is insufficient recognition of non-rational needs in any given society, and when extreme forms of control prevent individuals from gaining any gratification in their instinctual desires, there eventuates a society built on 'neurosis' and 'anxiety disorders'. Whilst civilisation provides institutions such as 'work', 'community' and 'family', which becomes the basis for the moral and judicial branch of personality known as the 'super-ego', only a certain amount of protection against suffering can be ensured (Freud 1963:16).<sup>12</sup> As Freud later points out if the loss of instinctual pleasure 'is not compensated for economically, one can be certain that serious disorders will ensue' (1963:34).

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the trouble, and that the outcome of it can only be a state of affairs which the individual will be unable to tolerate' (1963:82).

<sup>11</sup> Repression is defined by Freud as a mechanism adopted by the personality, in which barriers are set up to prevent the instinctual desires of the 'id' from making its way to the consciousness of the individual (Freud 1963).

<sup>12</sup> The superego is seen as a foundation for the rechanneling of instinctual energy.

Weber's theory of disenchantment, an outcome of industrialised society, links to Freud's theory of neurosis. Weber shows the extreme rationalistic tendencies of capitalism as having disturbing and destructive tendencies upon the individual. In Freudian terms, the strong limitations placed on the instinctual desires of the Calvinist believer meant that it was necessary to re-channel and deflect innate desires, which could not otherwise be satisfied in social settings. Consequently the Calvinist distrust of the body and sexuality ensured that there was plenty of energy available in other activities, to which this energy could be directed. Yet, Freud would no doubt view the obsessive calculation of rationalistic pursuits and methodical systems, which became the centrepiece for capitalistic endeavours, as being the result of excessive repression. Finally, if we are to link Weber's disenchanted society to Freud's theory of repression, then the following statements can be made: The greater the force of rationality, control and limitation placed upon the worker, which can be seen in technological machinery, assembly lines and the doctrines of Calvinism, the greater the level of repression needed upon the instinctual nature of the individual. Consequently, in the excessive control and manipulation of creativity and spontaneity, there results an extreme form of neurosis in the form of 'disenchantment'.

In attempting to link all this back to women with breast cancer, attention must be given to the impact a calculated world has on those trying to cope with illness. A person's identity, in the midst of a sick body, is unable to meet the demands of a culture bent on solutions,

While we feel that science and medicine can no longer protect our bodies from disease, leaky bodies have far more fundamental implications: leaky bodies endanger society...Is it the leaky, unreliable, troublesome body which threatens to overwhelm society? Women's bodies, old bodies and sick bodies may defy containment: these bodies may leak and spill. (Seymour 1998:166)

In hindsight, some women with breast cancer may perceive the modern world as a place that holds little value for their out of control bodies. Yet, can we generalise and say that in the twenty-first century all women are unable to identify with the sacred because they live in a world that resembles an iron cage? What of coping? Can women rely on the transcendent as a means of battling breast cancer, even if they are surrounded by a biomedical view of illness? If our society is so obsessed with science and reason, does this mean that we must dispel the power of divine forces in facilitating a sense of achievement within? This leads me to detail a story of an unwanted child noted in a biography of Mother Teresa (Rai and Chawla 1996). In this biography Mother Teresa discusses with the author an incident that took place with a young girl who came to her door late one night. She states,

Some weeks back, at midnight, I heard a child's cry at our gate. When I went down, I saw this little one. I don't think she was more than seven. Crying she said, "I went to my father and my father did not want me," and she crossed the road and went to her mother and her mother did not want her. "But you want me," she said. (p.73)

Belonging, love and the triumph of the human spirit can still be found in our secular world, even if certain theorists believe this to be impossible. Each of us wants to belong to something far greater than facts, or figures and not all of us find work meaningless and absurd. Women with breast cancer may see their work as important in their recovery from illness; work may also seek to connect women with a spiritual force that can generate hope for the future. Understanding the role of work in facilitating coping is examined more closely in the narratives of women.

## Conclusion.

The feeling of belonging and being loved by those around us is essential for survival. As seen in the story above, the young girl wants desperately to be embraced and accepted by someone. In being abandoned by her own parents, this child finds comfort in a woman of great faith; in finding solace in the arms of a complete stranger, this young girl feels wanted. When our deepest fears are met, when we are in need of comfort, we often turn to someone or something to achieve this. Women with breast cancer need some type of source that will enable them to feel good and wanted. A large percentage of women who come to accept newfound identities, who rise above the dread and disharmony that accompanies chronic illness, can achieve a sense of hope for the day that lies ahead. Depression, anxiety, occasional thoughts of suicide and feelings of helplessness can be overcome when women find a connection with a greater power (Koenig *et al.* 1988). When a belief in something almighty is experienced, identity can be restored from a raging and uncontrollable fire, to a glowing light that seeks to illuminate a weakened soul.

Global faith too must be discussed here. A feeling of belonging from within is more likely to be encountered in the presence of a sacred force; global faith can provide a sense of inner peace and contentment from emotional distress. Kierkegaard (1985) writes on this very theme. Kierkegaard's knight of faith is able to direct his love at God when faced with the act of sacrificing his only son Isaac. Belief in a higher being can therefore provide a framework in which to think and act. Simmel (1997) too sees faith as playing an essential part in allowing individuals to find completeness in the fragmentary nature of their existence. Simmel's notion of religion or what he calls piety is aligned to an attitude or a perspective. Simmel believes that the way in which people look at the world and their surrounding forces will determine the quality of life lived. He writes,

If we believe in another person or in God, we cause the unease and insecurity that is our universal destiny to feel to be replaced by a sense of stability directed towards these objects. The idea of this person or of God is a tranquillising force amid the stormy ups and downs of that soul. (p.168)

Simmel therefore expounds a powerful theory on the potential significance of faith in perpetuating a state of deep-seated calm and stability. Tensions and the disharmony of emotions can be resolved, or even clarified in the presence of a spiritual state of existence. Dread at the thought of dying, dreariness at witnessing a deformed breast can thus be battled when there is an element of inner strength and direction. In the words of Kubler-Ross (1978:13), 'It is fear and guilt that are the only enemies of man, and if we have the courage to face our own fears and guilt and unfinished business, we will emerge more self respecting and self-loving and more courageous to face whatever windstorms come in our direction'. Belief and faith can therefore be seen to impact on health and disease by empowering many women to take charge of the decisions they make.

When a person's identity is challenged due to unforeseen circumstances, he or she may feel uprooted from the pattern of living and from the perceptions of what makes up their character. This chapter has attempted to investigate what is meant by the term identity and how a fatal disease such as breast cancer can have a huge impact on reshaping and redefining the boundaries of identity. Global faith has surfaced again. Global faith and identity are closely linked. In the event of a battered identity, there evolves a fragmented sense of self which can impact upon coping with illness. Therefore, understanding the role of global faith in enhancing, or providing stability to the identity of women interviewed in this study is paramount.

Earlier on in this chapter it was also mentioned that narratives are essential to comprehending the plight of women afflicted with breast cancer; narratives expound their means of coping with the possibility of dying. Women's narratives are used in

this research as a tool for examining how these women cope with breast cancer. Yet, prior to approaching the women in my study, it was essential that I understood the impact of cancer in people's lives. In order to familiarise myself with the nature of cancer, dying and illness, I spent two years as a volunteer working with palliative patients. The following chapter is an account of my experiences with dying people.

## **CHAPTER FIVE: THE VOLUNTEER IN THE HOSPITAL**

### **SETTING: AN INSIGHT INTO THE NATURE OF DYING IN AN INSTITUTION.**

#### **Introduction.**

A central concern of this thesis is to investigate the role of global faith in helping women in this study to maintain a state of optimism and acceptance towards their illness. Researchers, who become involved with ill people, must be careful in their approach. Awareness of the various ways in which dying and disease impacts upon sick people is essential if research is to be carried out on the sick and dying. This leads us to the main reason for this chapter. Prior to entering into a research field, it was vital that I gain some experience with the nature of illness. In a bid to familiarise myself with these themes, I became a palliative volunteer in a hospital for two years. Through participating in volunteer work I was able to gain a greater awareness of the process of dying.

Volunteer work done within a social community is a valuable task to undertake. The volunteer worker has the fortune to encounter a variety of interesting people. As a volunteer, I became aware of the intricate side to death and dying through connecting and bonding with dying patients. By means of touching, talking, holding and listening to patients, a greater awareness of the process of death and dying was achieved. In my dealings with individuals whose lives were troubled by cancer, I saw with my own eyes and felt with my own heart what it means to have hope when all seem lost.

During my volunteer work it also became apparent how easily a dying person can become overwhelmed by illness, how love for life, ambition for healing, can become lost in a sea of hopelessness and futility. Further, I soon realised that a spirit of dread

and disintegration often engulfed those who were unable to deal with their fears of dying. As a result of negative and destructive feelings the 'spirit' within the dying person was often crushed and annihilated. In the event of patients not coping with their terminal status, they soon became angry and scared. As a result, dealing and facing the dying process became for some an incredibly frightening task. Terminal illness affects all facets of patients' lives — their psychological, physical, social, cultural and spiritual states of existing become challenged and distorted. Meanings patients attach to their illness will also determine the ways in which they view their condition. Most importantly the way one perceives illness will reflect the extent to which one appropriates an understanding of the nature of the situation. Meanings attached to illness will impact upon the degree of suffering encountered by the dying. Some individuals are able to embrace their fate, whilst others are not. In saying this I mean that there were some patients who right up to their death, denied they were dying. In this sense they had not come to terms with their prognosis and had left behind a number of unresolved issues. Other patients were realistic about their terminal condition and accepted their death in a positive way. For such individuals, coming to terms with their dying helped them to appreciate the time they had left. Being realistic with their fate also meant that certain problems could be properly dealt with.

The volunteer in the palliative ward has the *privilege* of learning about the ways in which dying people deal with the final stage of life. In being allowed to enter into the lives and traumas of the terminally ill, volunteers bear witness to the various ways in which individuals deal with sickness and dying. Such an experience allows the volunteer to understand what characteristics best make-up a 'good death' as opposed to a 'bad death'. A good death can be defined as a death which is accepted by the patient, where feelings of anger, denial and fear are resolved. Those willing to embrace their death will often reflect on their lives and take comfort in the wonderful

memories they may have. Further, settling family disputes, having a say in funeral arrangements and finalising a will, can provide dying people with a sense of closure and personal satisfaction (Ruitenbeek 1973). A bad death is the complete opposite of this whereby the dying individual is unable to accept his or her condition and as a result of this suffers from anxiety and turmoil right up to the moment of death. Those who are young and are leaving family and friends behind are often bitter and resentful of their condition. Individuals who feel that they have just started to achieve the goals they have set in their life may be unwilling to accept their fate. There is then the parent, who will leave their child or children behind. The terminally ill patient, who has only months to live and who has a young child, will never see their grandchildren, will never watch their son or daughter ride their first bike. Parents will often feel cheated when they can no longer be there for their children to guide and protect them from harm. In these cases, dying can be hated, spat at and struggled with.

There are then some terminally ill patients who are in a state of denial. Toyrbec *et al* (1968:43) write of those unwilling to deal with dying,

Even though death is recognised as inevitable and even age, infirmity and loneliness have shrivelled the prospects of happiness, there still comes a sense of loss and sadness when it is clear that life really will be over soon. For people who have clung too firmly to the comforting belief that their death must be a long way off, or for those whom the realisation of dying has come too expectedly, abruptly or harshly, this awareness may come as a great shock. It is too much to bear, the mind often takes refuge in denial once again.

One of the doctors on the ward once told me that denial is not necessarily a bad thing. If a person is able to find a place of peace or security in his or her state of denial, then at least he or she may find some comfort in unrealistic thoughts. For such patients, it was often family and friends who suffered. Certain questions could not be raised, and issues in need of resolution were buried with the patient. In the case of denial, death was something to be shunned away; death was unspoken of and ignored. It is imperative that a volunteer is aware of signs reflecting the various

stages of the dying process. Awareness of the dying process can help a volunteer to assist a patient with his or her transition into death even if a patient does not want to admit that he or she is dying. There can be no greater gift one can give to another than to help a human being to die in a calm and reassuring way.

Working with the dying gives volunteers a direct opportunity to practice compassion in a situation where it is needed the most. The importance of administering compassion to those dying, is outlined by Rinpoche (1992:190-191),

Your compassion can have perhaps three essential benefits for the dying person: First because it is opening your heart, you will find it easier to show the dying person the kind of unconditional love I have spoken about, and which they need so much. On a deeper, spiritual level, I have seen again and again how, if you try to embody compassion and act out of the heart of compassion, you will create an atmosphere in which the other person can be inspired to imagine the spiritual dimension... On the deepest level of all, if you do constantly practise compassion for the dying person and in turn inspire them to do the same, you might not only heal them spiritually, but perhaps even physically too.

According to Rinpoche, compassion is essential in helping to heal the pain brought on by dying. Compassion can also help to mend a terrified heart and a disillusioned spirit. Emotional and physical sufferings, which burden the terminally ill, can be eradicated through acts of kindness, love and tenderness. The sick person's fear of dying, in the presence of compassion, can be destroyed and replaced by a sense of well-being and peacefulness. Yet, while Rinpoche writes of the benefits of compassion for the dying person, it is often difficult to carry out compassionate acts to those who want to be left alone. There have been many patients in the palliative ward who have not wanted to connect or bond with the hospital staff, chaplains or volunteers present. Many dying people do not want strangers interfering with their remaining time and would prefer to spend their last days on their own. It is the patient's right to not want to have any spiritual, or emotional involvement with those individuals who offer compassionate acts. Refusing compassion does not prevent patients from attaining an enlightened state of being. It is possible for some patients

to rely on their own resources as a means of adequately dealing with the process of dying. Such patients must be respected and must not be pressured to rely on outside sources as a means of coping with their terminal condition.

This chapter details my experiences with dying people. It must be stated again that it is only in having the opportunity to have encountered these patients that a deeper understanding of the plight of the terminal patient has been achieved. Had it not have been for this experience, my insight into the nature of dying would have been severely limited and confined to textual explanations. While my research question deals with women, breast cancer and faith, the aim of this chapter is to detail an investigation into the dying process. Further, as a volunteer it was made clear from the beginning that I was permitted to question individuals on how they saw the role of faith in the dying process. Rather, my role in this ward was to simply be there for patients in the form of a listening ear and a person whom they could confide in. Hence, while this section may not directly deal with patients who are diagnosed with breast cancer, it does deal with a practical experience in the area of dying. In having encountered this experience, I have reached a heightened perception of the nature of my topic and am now in a better position to seek possible answers to the questions I have raised so far.

### **The Role of a Volunteer.**

Palliative care refers to care that is provided on a continuous basis to those patients for whom cure is not an option. In palliative care, all the medical and nursing needs of the patient are catered for alongside psychological and spiritual needs. One of the aims of the hospital setting, when dealing with the terminally ill, is that it strives at all times to maintain hope in a fairly difficult situation. Care in the palliative ward also looks to alleviate discomfort and other symptoms encountered with chronic illness. It

is therefore important that patients in palliative care are able to live their remaining time in a relatively painless way. Maintaining an open and honest attitude with patients, respecting their inner thoughts and beliefs, alongside being unconditionally accepting of their convictions, is of major concern in the palliative ward.

Ensuring that patients are stress free and have a positive outlook to their illness is also of vital importance to the medical team. In the case of anxiety and depression, the hospital aims to alleviate distressing feelings encountered by the patient through a number of sources. The palliative care service is conducted by a multi-disciplinary team involving professionals such as; physicians, nurse co-ordinators, nurses, social workers, occupational therapists, physiotherapists, chaplains/pastoral care, dieticians, psychiatrists and psychologists. It is expected that these professionals employ a holistic approach to patient care, with emphasis on the quality of a patient's remaining life. Team members within the palliative care service must also cater for the needs and rights of dying patients. Some patients are released from the hospital to die at home. The importance of maintaining terminally ill patients in their own home surroundings, for as much time as possible, is also viewed as essential for effective patient care. The reasoning behind this is that patients often prefer to die in their own comfortable surroundings. Hospitals in this case are used in the last instance when pain needs monitoring in the confines of a medical setting.

The main purpose of a palliative care volunteer is to strengthen a patient's ability to cope with the quality of their life until they die. It is necessary that palliative care volunteers provide comfort and companionship. Despite the many advances in physical care, terminally ill patients still suffer a tremendous amount of anguish and grief due to their tragic situation. Unwanted feelings of inadequacy, depression, and distress are commonly felt by the dying. Further, feelings of being unable to cope with the situation are often encountered by those diagnosed with a terminal illness.

When having to deal with the pain of dying, being given the opportunity to discuss personal fears can be of benefit to patients. Volunteers provide patients with the opportunity to discuss worries pertaining to illness. In talking with volunteers, patient anxieties and fears relating to illness may be eased. Fear of death, fear of being left alone, fear of leaving behind loved ones, are only a few emotions which are commonly felt by the dying. A community worker, who is willing to take the time to just listen, can help in providing comfort to the weary and distressed patient. Lichter (1967:19) states,

Listening to the patient's questions gives indication of his thoughts, his feelings and his needs. With increasing confidence that his questions will be taken seriously and answered with care, he will gradually feel more able to discuss his situation and face reality.

By simply being there, volunteers can provide sick patients with the opportunity to discuss personal concerns. In creating a setting whereby the sick are free to let loose their deepest fears, volunteers are able to offer support and guidance during the final stages of the life of the terminally ill. Often, volunteers are able to help patients who do not have the strength and courage to face a terminal illness. Patients who feel isolated, who find it difficult to come to terms with the loss of independence, who are unable to cope with the loss of their security and future existence, may find it comforting to talk to a volunteer. Thus, the role of the volunteer carries a tremendous amount of responsibility; the volunteer is able to offer many dying patients comfort from suffering when their inner emotions bombard them with negative states of thinking.

Yet, a volunteer can only be aware of patient needs if the patient is given the opportunity to make his or her needs known. Any severe restrictions to communication can in turn affect the relationship between patients and volunteers. In order to construct an atmosphere of confidence, in which patients are able to talk about their concerns and feelings without reservations, it is necessary that volunteers

perfect communication strategies. Effective communication by the volunteer can help to establish a sound relationship with patients who are dying. Positive interaction involving talking, listening and connecting allows empathy, understanding and reflection to occur in the discourse process. At a deeper level of skilful communication there must be an awareness of those factors in the management of negative emotions. Dread, fear and a number of emotional problems encountered by the sick and the dying must be addressed when interacting with patients. Often ignorance, insensitivity, and reluctance on the part of the volunteer to deal with such emotions can affect the psychological and emotional state of a dying person. Understanding what patients and families go through, in the lead up to dying, is of value when administering competent care.

Whilst volunteers in the palliative ward perform a number of tasks such as shopping, respite for family and caregivers, transport to appointments, outings, companionship, assistance in daily living activities, the main purpose of the palliative care volunteer is to strengthen patients' abilities to cope with life. In addition to this, it is necessary that palliative care volunteers provide sincerity and empathy to those they serve. Honesty is also needed if the relationship between a volunteer and patient is to be successful.

### **Expectations Placed on Volunteers.**

*Before I detail my volunteer experiences in the palliative ward at North West Hospital, I will outline the expectations placed upon volunteers in the hospital setting.*

Three years ago I began a training course at a hospital that catered for palliative care volunteers. On the first day I was given a handout which outlined what was expected of volunteers who worked with the terminally ill in a hospital setting. Here are the exact words printed on the handout.

### **Volunteers at Work.**

- Volunteers compliment [not supplement] MEDICAL, NURSING, PARAMEDICAL STAFF
- Volunteers must be sensitive to patient needs.
- Volunteers help bridge the gulf between the professional/institutional world and the known social world of the patient. Volunteers must be seen to be life giving in the presence of a patient's perception of the institution.
- Volunteers provide a richer dimension to palliative care.
- Volunteers reinforce 'normal' human needs alongside the social, cultural, emotional and physical needs of the patient.
- Volunteers help reinforce the patient's status as a continuing member of a family and the living community at large.
- Volunteers offer general support to family and friends of the palliative patient.
- Volunteers act as consultants to other community services.
- Volunteers participate in fundraising activities and show a special interest in the following services, relaxation/creative, and bereavement.
- Volunteers must be sincere, warm, compassionate and empathetic.
- Volunteers must be non-judgemental and non-discriminatory in their approach to patients.
- Volunteers remain objective in that volunteers must not let their own experiences interfere with their work at the hospital.
- Volunteers have a commitment.
- Volunteers accept communication as integral to role.
- Volunteers understand motivation and reasons to accepting volunteer role.
- Volunteers have a balanced quality of life.

From the points raised above it is clear that choosing to be a volunteer worker in the palliative ward is not an easy task. There is a lot expected of volunteers. They must not only provide a service to patients and families, but more particularly, they must be seen as providing a link between the hospital (illness) and community (wellness — normality). It is expected that volunteers take a balanced approach to their role within the hospital. Personal and emotional problems of volunteers should not interfere with their duties performed in the palliative ward. While it is understandable that many volunteers may at times find it emotionally difficult to be constantly interacting with dying people, it is vital that helpers create a balance of life and living in their own minds. The reason for this is that it is very easy for volunteers to become overwhelmed by the whole process of dying. If volunteers have not themselves properly dealt with their own experiences of dying, then this can affect their relationship with patients. Volunteers who have developed a rapport with their patients must also be able to deal with patient deaths when the time comes.

Volunteers need to discuss emotional feelings relating to the deaths of those they have cared for. If volunteers are to provide positive support and care while working with the dying, it is imperative that they have a heightened awareness of how to deal with their own emotions to dying.

Volunteers must also be sensitive to how their actions may affect patients. When working with dying people, volunteers must be prepared to meet the various reactions of patients. Lichter (1987:31) details common fears encountered by many cancer patients,

The cancer patient is frightened about what is happening to his [sic] body. Perhaps most of all he [sic] fears pain. He [sic] may fear what he [sic] considers to be unnecessary investigations and he [sic] may be afraid of proposed treatments. He [sic] may fear disfigurement, loneliness, helplessness, neglect, indignity; he [sic] may fear loss of work and financial difficulties. He [sic] fears that he [sic] will be cut off from families and friends... He [sic] may fear that he [sic] will not be able to talk about his [sic] deepest concerns, anxieties and fear. He [sic] may fear death. He [sic] fears the unknown.

Such fears are fairly common in the hospital ward and a volunteer must be aware of vulnerable and scared patients. Allowing a patient to feel comfortable in discussing his or her fears is important to the volunteer. Yet, whether or not a patient confides in a volunteer is dependant upon the level of sincerity and humility bestowed upon the terminally ill. Patients need to feel that they can trust someone enough to share their burdens and worries relating to dying. If trust is established, volunteers are able to spend quality time with patients and attain a sense of accomplishment in their charity work. Those volunteers, who are genuine, caring and courteous in their approach, will be valued. They will more than likely establish sound and rewarding relationships with dying people and in the process understand the true meaning of courage.

### **Volunteer Work in a Palliative Ward.**

When I was a child I thought that death was an easy and simple process. When one's time was up, one simply died and that was that. Further, notions of 'the beyond', 'the domain of eternity' symbolised a state of existence which transformed suffering to peace. In the magical realm of infinity, the loneliness of dying was eased; the dread of separation from the living was comforted and the fear of new grounds was transposed into a horizon of unlimited possibility and real freedom.

As I saw death at the age of four, if a lifetime had been well spent and honestly lived, the pearly gates of heaven would be there to ease the desolation and despair accompanied with the loss of life. Death then, was not to be feared for some, but rather seen as a voyage of discovery that would lead to a different state of feeling and thinking. Only those who had committed evil and unforgivable crimes would be denied access to this medium of enlightenment. And human beings, who inflicted pain and misery on others, would lie forever in darkness, forever faced with the horror of their sinful deeds. An uncontrollable and ferocious inferno awaited them and the fires of hell lay ready to scorch and destroy their malevolent and spiteful souls.

As an adult, my views concerning death and dying have somewhat changed. Having participated as a volunteer I have attained a greater awareness of the nature of dying. In the past two years my work in the palliative ward has taught me a number of important things. The environment surrounding death will inevitably shape the way in which terminal illness is perceived; a dying person's frame of mind will ultimately determine whether death is viewed in a positive or negative way. In the event of a terminal prognosis, transcendence from pain and suffering is reflective of the meanings attached to dying. Often victims of terminal cancer, unable to accept the situation of dying, unwilling to journey through dying in a sacred way, will face death

with dread and horror. The individual who does not come to terms with dying, who abandons all hope and faith of enjoying the remaining time he or she has, will more than likely view illness as a savage end to everything held precious.

Death is situational in that 'the way one dies is a reflection of the way one lives' (Moller 1996:4). For a dying individual, being surrounded by loving and supportive friends and a warm secure social setting can be of benefit when coming to terms with dying. The institutionalised depersonalisation of death and dying, alongside bureaucratic routines of the dying process, is symbolic of the hospital ward today. As Moller (1996) states, 'Dying as a human process becomes managed and is regulated by a group of emotionally detached professionals. In this way, the ending of an individual's life becomes the province of medical managers' (p.29). In the hospital setting, dying people connected to tubes, wires, heart monitors and life saving equipment, are bombarded with the rationalisation and scientific management of death. The management of dying patients in the hospital ward is often a reflection of modern society's attempt to tame and conquer the process of dying. It has been argued that a technical orientation of patient care found in the hospital setting serves to estrange the dying patient and to facilitate personal detachment and powerlessness (Moller 1985). As a result of this, the remaining time left for a terminally ill patient often becomes isolated whereby the act of dying is placed in the hands of medical professionals and scientific reasoning. In encountering the modern organisation of dying built on bureaucratic and technological foundations, the dying movement for many can be viewed as something to be regulated and controlled by outside forces.<sup>13</sup>

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<sup>13</sup> Max Weber details the extent to which rationalisation, specialisation and the development of scientific rationale, has created a sense of depersonalisation for members of society. As Weber observes, with the establishment of bureaucratic ties within social institutions there has emerged an overtechnologized treatment of people in general (Weber 1968:196). In relating this to the hospital setting, the following can be said, an attempt by bureaucratic agencies to shift the dying process away from family ties and social networks has meant the adoption of alienating means when dealing with the dying.

A number of authors have argued that the meanings constructed around health and illness affect how people respond to their situations. Giddens argues that feelings of ontological security find their framework and substance in a 'practical consciousness' of the meaningfulness of our day-to-day actions (1991:36). Yet, in the face of trauma and crisis, this reality may be challenged especially if an individual is confined in a strange environment, with unfamiliar people. For many patients at the hospital, being confined to a health care institution has removed them from those precious things that give meaning and purpose to their lives. The hospital ward removes a great proportion of the social structures entwined within the patient's lifestyle. Family, friends and social networks, which often provide dying individuals with the emotional strength to deal with illness, are isolated from the dying patient.<sup>14</sup> Although visiting hours in the hospital setting give patients an opportunity to unite with friends and families, this time is limited and is regulated by nursing staff. While visitors are a source of entertainment for patients and provide love and support for those who are desperately ill, the time they spend in the ward is monitored. The bell rings to inform visitors that it is time to leave; they are no longer allowed to stay with the patient.

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Kubler-Ross (1997) holds similar views to that of Weber. According to Kubler-Ross, the increased value of scientific and technological rationale on the dying patient is destructive to human needs and human wants. In the beginning of her book, she begins by lamenting the lack of sensitivity and compassion in the present day treatment of dying people. She believes that an increased dependence on science and technology has led to a standard of care that is callous and heartless. Dying in the rational environment becomes lonely and impersonal because the patient is often taken out of his or her familiar environment and placed in a setting which is totally foreign and alien. She states,

He may cry for rest, peace and dignity, but he will get infusions, transfusions, a heart machine, or tracheostomy if necessary. He may want one single person to stop for one single minute so that he can ask one single question-but he will get a dozen people around the clock all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being. (p.22)

Where dying was once the responsibility of family and social networks, whereby family members cared for their terminal relatives, the responsibility of the dying process has somewhat changed. In modern times dying is monitored and controlled by medical professionals who operate under the directions of specialised institutions.

<sup>14</sup> In previous eras, it was the responsibility of the community and the family to care for the dying. During the Victorian era, death and dying held a deeply significant place in human culture. The Victorian deathbed differed from other eras in that it embraced suffering and dying with romanticised notions. Further dying people were surrounded by immediate friends and family during their last days and made to feel as though they were supported by their local community. In modern day society, the dying process is no longer controlled by close family members or the general community of friends and loved ones. Even funeral rites have ceased to be a concern for the public as a whole as families must now rely on funeral specialists to organise the burial proceedings (Huntington and Metcalf 1979).

When patients are deprived of a social well-being made up of, children, friends, a wife, a husband, parents, work colleagues, neighbours, they are once again left to face the night on their own.

Expressions of anger are normal responses for those who grieve the loss of not only their healthy bodies, but also their energetic lifestyles and independent states of existence. To be told when to eat and when to take medication, to have to wait for assistance from a nurse in order to urinate or defecate, are for many, a humiliating experience. Having to be assisted to the lavatory and to have underclothes physically removed by a complete stranger can evoke feelings of shame for the patient concerned. Further, when patients are passed a bedpan and are expected to carry out bodily functions behind closed curtains, embarrassment and disgrace are generally felt. Thus, the act of carrying out a normal bodily function can become, for some, a dreadful ordeal. To have to sleep in a strange bed within the perimeters of a foreign environment can also cause alarm for many dying patients. It must be remembered that a great proportion of dying patients, prior to getting sick, had slept with their partners for many years.<sup>15</sup> Within the boundaries of their own social domains, the comfort of a loving embrace from their husband or wife enabled them to sleep relatively securely at night. Yet, within the hospital realm, patients must sleep in a single bed. As a result of this, many of the terminally ill find it extremely difficult to adjust to their new sleeping quarters. Indeed some are afraid to sleep at night. As a

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<sup>15</sup> All of the patients in the palliative ward were aged between forty and ninety years. This meant that a great proportion of patients had been with their partners for a long period of time. Thus, having to adjust to not being able to sleep with their companions was a main concern for many terminally ill victims. For many patients, being forced to sleep with other patients, being separated at night from their loved ones, caused feelings of isolation and disconnection. Thus, sleeping in the ward became an ordeal for many. Nightfall no longer provided a spiritual and physical closeness to their spouse. Instead, in the hospital ward, sleeping was symbolic of an environment made up of foreign sounds, unfamiliar people and a detachment from those they loved. For those who had spent the last thirty years resting the night with their loved ones close to them, the hospital bed represented a coldness of spirit that disempowered them from all that was held precious and dear.

result of being unable to sleep with loved ones, feelings of insecurity and loneliness are often felt.

In addition, sleeping in an unfamiliar environment can present the terminally ill with a number of fears. Some of these fears involve dying during the night and having no one there to hold their hand. Other fears involved being disturbed during the night by dementia patients who were disorientated and sought refuge in their beds. Further, sounds of people coughing, the hum of ventilating machines, restless patients unable to settle down quietly, made it difficult for patients to get a good night's rest. Twilight then for various sick individuals offered little peace from suffering. Rather, nightfall, with its accompaniment of unfamiliar sounds and unusual behavioural patterns, sought only to cause emotional upset and distress. Under such circumstances, it is easy to see why a great proportion of patients feel that they have very little control over their illness. This is especially so if they are treated as a bed number, or a diseased individual, instead of a person whose feelings and emotions are of significance and importance.

It is not uncommon for patients to be in hospital for six months at a time. As a consequence of this, patients develop both positive and negative ties with other patients who share their ward. Good ties shared between the terminally ill, may involve being able to chat to the person lying beside them about trivial or meaningful things in their lives. As a result of this, patients establish friendships with other patients. Thereinafter, bonds are established between the terminally ill whereby acquaintances are created and attachments are made. Negative ties may involve having to endure the demented patient who frequently screams during the night and prevents others from resting. Being forced to share a room with a patient unable to cope with their illness can also be unsettling to others who bear witness to this. Some patients cry openly for their missing wife, or husband, and show signs of giving up on

life. Others show signs of depression in being forced to stay in a hospital because of medical reasons, when they would much rather be with their family and loved ones. Crying for a wife who no longer shares his bed, crying for the loss of a home because a bed in a nursing home awaits them, crying for the loss of one's independence, are frequent occurrences.

Further, patients openly grieve the loss of their healthy bodies and identities they once had. A loss of their identity whether it be the identity of the nurturer, the breadwinner, the husband or the wife, contributed to overwhelming feelings of resentment and anger. Often, patients who felt cheated and robbed of a significant status or role, displayed aggressive outbursts in an attempt to regain some power over their lives.<sup>16</sup>

The social existence of patients is often reduced, and sometimes more or less eliminated in the hospital setting. The dying patient commonly experiences isolation, emptiness and loneliness. During my time at the hospital, I have seen cancer patients admitted into the palliative ward in reasonably good spirits. The first week of their stay is often associated with a need to settle into the hospital routine. New patients often feel it important to familiarise themselves with medical staff members, acquaint themselves with other patients, and most importantly adjust to their new surroundings. Upon entering the hospital, some are in full control of their bodily functions and are able to walk relatively freely (often without the aid of a cane, or walking stick). Terminally ill patients, who are capable of walking, are given the

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<sup>16</sup> At the hospital where I did my volunteer work, it is not uncommon for a patient to have to come to terms with the death of another patient in their ward. It was often the case that many sick patients had to deal with the death of those they had slept beside for many months. Many of the terminally ill, who developed a rapport with other patients who had died, often found it incredibly difficult to accept their deaths. Therefore, the hospital sought to also force the dying to deal with those who had already died.

opportunity to meet other patients who are bed ridden.<sup>17</sup> Such exercise for many mobile patients is very important, as walking is viewed as an activity which signifies independence. Yet, unfortunately, for those who are immobile, the wheel chair can bring with it a great deal of negative attitudes. To be confined to a wheel chair for many, is to reach a state of extreme humiliation. Invalid patients who must rely on nurses to take them to the toilet, who are unable to shower and dress on their own, quite often encounter destructive emotions, which can lead to depression and a feeling of helplessness.

### Conclusion.

Having worked with dying people and having gained a deeper understanding of how dying affects the terminally ill, I am now in a better position to enter into my own research field. I can now begin investigating the role of global faith in facilitating coping with breast cancer. Can global faith enable women in this study, who have breast cancer to reach a state of personal well-being and inner peace? Does global faith help to resolve unwanted feelings such as anger, depression, grief and vulnerability? Does global faith exist in the lives of these women who are faced with a life threatening disease? What is the role of global faith in helping them to come to terms with identity and body image? The following chapters attempt to examine these questions in some detail.

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<sup>17</sup> Patients, who are able to meet and establish a support network with other patients, are able to discuss fears and hopes of their illness. In partaking in this exercise, many patients are able to unburden anxious thoughts relating to their illness. In doing so they are given insight into others who are experiencing the same kind of emotional turmoil. A great proportion of patients, who are aware that other dying people experience the same level of emotional and psychological pain as themselves, recognise that they are not alone in their suffering. In being aware that one's immense torment can be really understood by others who are also experiencing this misery, can be of some support in enabling acceptance of one's illness.

## **Chapter Six: Methodology.**

### **Introduction.**

In examining how the women interviewed for this thesis cope with breast cancer and the role of global faith in their coping, it is essential to adopt research strategies that explore how life problems are dealt with. This chapter outlines the methodology and data collecting practices that are used in this study and begins with a discussion of research techniques. This chapter also serves to make note of the various limitations of this thesis imposed by sample, coding techniques, style of interviewing and the methods adopted to analyse and transcribe data. The restricted and selective way in which religiosity and faith are presented and noted in chapter seven is also given some consideration.

### **Research Techniques.**

Qualitative research methods are favoured in this research design because they enable a richer analysis of participants' feelings and emotions that might not otherwise be possible using quantitative techniques such as surveys or highly structured questionnaires. This study aims to attain information from participants by means of listening and probing. A more accurate picture of the world of others and their subjective states of thinking and existing is attainable when participants are given the chance to talk freely in a comfortable environment.

Qualitative research allows the substantive area of study to surface in its social setting. The use of data collecting techniques such as the interview process, which examines people's words and actions in narrative or descriptive ways, will be relied upon as a means of gathering information pertinent to the study at hand. The interview process allows insight into the ways cultural values and social relations

shape human thoughts and perceptions. Looking closely at how individuals construct meaning from actions can be achieved by means of using the interview as a method for obtaining data. Bulmer (1977:278) states,

The fact of the matter is that we cannot observe everything. We cannot observe feelings, thoughts and intentions. We cannot observe how people have organized the world and the meaning they attach to what goes on in the world. We have to ask questions about those things. The purpose of interviewing, then, is to allow us to enter into the other person's perspective.

Research techniques that elicit spontaneous and meaningful responses are valued in this study. Data collection tools that are faithful to women's thoughts pertaining to illness, death, dying, body image and global faith, will be relied upon.

Bouma (1998:18) states, 'qualitative research tends to answer questions such as: What is it like to be a member of that group? What is going on in this situation? What is it like to experience this or that phenomenon? Hence qualitative data tend to be expressed in the language of images, feeling and impressions; they describe the qualities of the events under study'. Bouma's words hold relevance to the present study. When investigating the questions that are raised in the previous chapters, it is imperative that women are given the opportunity to be open when telling their stories. Individuals expected to answer a set of questions that list a series of multiple choice answers are not given the chance, or scope to detail their inner-most thoughts and feelings. As a consequence of this, autonomous responses are lost and 'voices' within silenced. Allowing women's voices to be heard and not ignored is an important aim in this research project.

### **HEARING WOMEN'S VOICES**

Julia Kristeva questions the role of language in silencing the voices of women. She is concerned with the various types of communication in our lives, believing that almost all can be traced back to texts. What is also important to note is that she believes that

verbal communication is the basis of our linguistic, literary and social theory. The language of verbal communication is referred to as the symbolic. The symbolic provides a structure for organisation, whereby it defines the boundaries and limitations. Through the use of language, society is able to create 'a fixed, governed word, ruled by a series of inhibitions and prohibitions' (Kristeva 1986:153). The symbolic order therefore has the power to designate hierarchies, to stipulate what is to be seen as the dominant discourse and what is to be interpreted as being 'The Other'. Women are shaped by the symbolic order; their existence is dominated and overpowered by way of linguistic mastery. Men are more often than not made to seem superior, more intelligent and exceptional in the use of language. They therefore retain the dominant discourse, superseding the voices of women.

In the development of hierarchies, women have been forced to hold back, restrain and control thoughts which oppose those values represented by the collective conscience. Such thoughts are silenced, repressed and pushed into the unconscious, forming foundations for the semiotic. The semiotic order has no speech, no verbal communication, stepping over the divisions between past and present, time and space. It is 'neither a before nor an after, neither true nor false, it neither judges nor postulates, but refuses, displaces and breaks the symbolic order' (Kristeva 1986:153).

The semiotic is linked with all that is feminine. For Kristeva and other feminists, such as Irigaray (1985), this label is problematic in that it sets preconceived notions on how women should naturally behave and think. Irigaray states 'a long history has placed women in the same sexual, social and cultural conditions' (p.164). Yet, women, just like men, hold different values, their perceptions are not identical. This study provides women with the opportunity to speak their own language, to communicate in their own discourse without the threat of being dominated by

conventional frameworks that reek with sexist dogmas, ethnocentric and patriarchal values. In providing an environment whereby women can discuss attitudes to life, breast cancer, coping and illness, women are able put aside conditioned responses and experience the free flowing of thoughts and ideas.

Further qualities linked to the feminine are not valued by the opposing order, as they are seen to be weak, vulnerable and powerless. In order for a woman to be accepted into the domain of the masculine she often silences her deep and innermost thoughts. Thus, it is undoubtedly essential that women are encouraged not to feel intimidated when talking about their beliefs. Reinharz (1992:18) is aware of the importance of women speaking for women when she states, 'this asset is particularly important for the study of women because in this way learning from women is an antidote to centuries of ignoring women's ideas altogether or having men speak for women'. Research on women's talk suggests that gender accounts for various differences in speaking and writing. For example, speech patterns, the use of adjectives and adverbs, pronouns and grammatical forms, vary from men to women (Lakoff 1975; Spender 1980; Thorne and Henley 1975). This thesis considers the ways in which experiences can be described in one's own terms. The Women interviewed in this study were asked to communicate their own expressions, in their own language. The women interviewed were encouraged to speak for and about themselves in order to focus on these women's testaments as lived.

Pearson (1985) writes that women tend to use more expressive and emotional language. Women rely on less aggression, profanity and violent terminology when delineating their opinion (1985:179-191). Maltz and Borker (1982) believe that women are often more inquisitive in interviews and ask questions, maintaining a positive interaction with the interviewer. This study has attempted to embrace differences in the expression of emotions and feelings and does not to assume that

we all think and feel the same way. The method of this research is to allow the experiences of women interviewed to be told according to their own interpretations. Their insights are valued and deemed important; their outlooks welcomed and respected.

Rather than researchers focusing on their own perspective as being the right one, it is the informant's account that must ultimately be sought and highly valued. In attempting to retrieve women's perspectives that are natural to them, a significant move from the interrogative process has been established. A more conversational style has been adopted as a means of providing rich, detailed data (Patten 1990). According to Oakley (1987), the use of conversations in collecting data can help the researcher to gain in depth access to the motives, meanings, actions and reactions of people in the context of their everyday lives. She states, 'in order for an interview to be successful, it must have all the warmth and personality exchange of a conversation with the clarity and guidelines of scientific research' (1987:33). As a result of the interviewer not using a specific ordered list of questions with specific highlighted responses, definitions and descriptions of social perceptions are captured more readily. In carefully considering ways of gaining information, a comfortable form of social engagement for the interviewer and the interviewee can be established.

Yet, while Oakley details the effectiveness of conversations as a means of gaining data, there can also be an element of risk if one adopts an overly friendly approach to the subjects. Getting too close to participants under study can be quite dangerous. When the time comes for the researcher to exit the field of study, participants may feel used. It is often the case that individuals, who have developed close ties with researchers, encounter a sense of abandonment and loss when the study ends (Bouma 2000:194). A participant, who has opened up his or her heart, shared deep emotions and thoughts with a researcher, can feel hurt if the researcher suddenly

ceases contact. Thus, there is an element of responsibility on the part of the researcher to maintain a professional relationship with those under study. A friendly, but distanced approach to women I interviewed was adhered to; their views, insights, stories and inner-most thoughts were valued, respected and treated in a professional and confidential manner.

In adopting a conversational approach to the interview process, it was necessary that I was familiar with and had knowledge of key themes linked to breast cancer. Considering the sensitive nature of the research project, great care was taken to ensure that I firstly understood the impact of cancer and terminal illness on human lives. Familiarising myself with issues linked to cancer such as illness, dying, identity, body image and treatment was essential. Participating in volunteer work in a palliative ward at a hospital for over a year helped to inform and educate me of issues linked to illness, death and dying. Completing a training course prior to interviewing women with breast cancer also helped in understanding how to approach these women. Experience in working with the terminally ill and those individuals seriously affected by cancer meant that I had a greater understanding of the impact of breast cancer in women's lives. My volunteer training also generated an air of confidence within both me and the women interviewed. Those women I interviewed were aware of my expertise as a Palliative Carer. At the commencement of each interview women were told of my training, which helped to generate a certain degree of trust in my capabilities as a researcher in the field of cancer.

### **Gaining Access into the Field.**

Once permission was gained from the Ethics Committee at Monash University to carry out my study, I set about contacting co-ordinators of breast cancer support groups in Victoria. Meetings with co-ordinators from three support groups were held.

For the purposes of confidentiality I have deliberately not included the names of these support groups. It was during these meetings that I was granted permission by co-ordinators to approach women in an informal way. It was my intention to first distribute questionnaires composed of open-ended questions (see appendix 6.1). The questionnaire presented a series of questions pertaining to diagnosis, perceptions of illness, positive support networks and faith. At the end of each questionnaire was a section that could be completed by those women who agreed to be interviewed at a later date.

Co-ordinators of support groups were given these questionnaires during the initial meeting. It was the co-ordinators' role to distribute questionnaires to those women wanting to participate in the study. Co-ordinators were asked to give out the questionnaires so that women would not feel pressured to participate in the study. Women were told by their co-ordinator that at no time would they be forced to partake in the research process and that they would not be treated differently should they decide not to complete a questionnaire.

The aim of asking women to complete the questionnaires was to allow them in the privacy of their own homes to respond to open-ended questions related to the way they were experiencing and coping with breast cancer. The questionnaire also gave them the option to be interviewed if they wished. Eleven women in the sample did not complete the questionnaire preferring to be interviewed. The remaining women, having completed the questionnaire, indicated that they would like an interview. The questionnaire was therefore a valuable tool in sourcing women who felt comfortable in talking about their journey with breast cancer.

Questions outlined in the interview were based on the women's responses to their questionnaires. The interview took on both a structured and unstructured approach.

Whilst there were a list of structured questions that all of the women were asked, there were also questions that emerged from their individual stories. All of the women were therefore asked a variety of questions pertaining to their particular experiences. The interview was also designed to expand on the written data already provided by those women who had completed the questionnaire. Women who simply participated in the interview were asked to comment on the questions outlined in the questionnaire. Data obtained in the interviews is outlined in the chapters that follow.

### **Sample.**

Twenty women were interviewed in this study. The ages of these women varied from thirty-two to eight-one years. The ethnic backgrounds of these women ranged also. All women spoke fluent English. The socio-economic background of women interviewed varied from working class to middle class. Of the sample, half of the women were professionals ranging from nurses, teachers, business, Salvation Army Officers, journalists, shopkeepers and supervisors. The religious backgrounds of women interviewed also varied. Some women were atheists and agnostics, while others attached themselves to Buddhism and Christianity. Given the small size of the sample I do not intend to examine how class, age or ethnicity impinge on coping with breast cancer.

As a result of the small sample of women interviewed, there were limitations in the data generated. Women's responses to interview questions, whilst valuable and insightful, did not reflect how *all* women coped with breast cancer. Instead, this sample permits me to draw attention to how some women coped with breast cancer, more specifically, a small sample of women who attended support groups. The voices of women who chose not to attend support groups, or who had only attended support groups for a short while, were not available to me.

The focus of this research is on the specific responses outlining how women cope with breast cancer in order to derive specific themes. For example many women interviewed discussed the importance of having a network of women who understood what it meant to live with breast cancer in the form of a support group. Another common theme identified by some of the women was how the level of medical care received by support group coordinators and visiting medical practitioners facilitated coping. Because the women interviewed did not mention such issues, this research makes no reference to the potentially damaging effects of support groups, or the negative experiences encountered by some women at these meetings.

In hindsight, a more generalisable response of how women cope with breast cancer could have been attained if the sample was greater and included women from a variety of social backgrounds. Yet, considering the delicate nature of the topic under investigation and my inexperience in researching the area of death and dying, it was extremely difficult to access women who wanted to discuss their experiences with cancer and dying. While it is fully understandable that many women would not and could not openly disclose their thoughts on a sensitive issue such as their dealings with breast cancer, this did however make my job of collecting data incredibly difficult. On a number of occasions I was flatly denied access to women because of my inexperienced status and one co-ordinator of a support group went so far as to say, "I am not letting you anywhere near my women". I later found out that this co-ordinator had discussed my thesis topic with other co-ordinators and had voiced her disapproval of my research because of my inexperience in this field. Again, I understand the need for co-ordinators to protect women from insensitive researchers who have little regard for the vulnerable nature of individuals faced with a life threatening disease. But my volunteer work was a sound basis for my introduction into this field. My two years as a palliative carer prior to entering the field and my

extensive training in this area meant that I was not a novice in my dealings with cancer patients. Rather, my training allowed me to become sensitive to the needs of women that I wanted to interview and I was steadfast in my careful approach to their illness. Such qualities are unfortunately unable to be ascertained in a telephone conversation.

Those co-ordinators, who allowed me to approach women in their support groups, placed clear restrictions on my relations with the groups. These limitations were consistent with the terms of the ethical approval granted by Monash University. I was not permitted to attend support groups on a regular basis. I was not allowed to contact women individually to ask them whether they wanted to participate in my research and had to rely on co-ordinators to discuss my project with them. I was not allowed to attend the social outings organised by support groups, whether it be dinner at a restaurant or a visit to the theatre. Therefore to many of these women who were introduced to my study, I was simply a researcher whose name appeared on a cover letter— A researcher who had no voice, no aura, no appearance and who wanted to pry into women's lives at a most difficult time. This leads me to make note of another limitation of this thesis. In not being able to do extensive participant observation at these meetings, I was unable to understand fully the role of participation in support groups in the way these women coped with breast cancer. In not being privy to their discussions over coffee when they spoke of how they managed their illness, in not being able to watch their facial expressions or their body language when talking with other women in the groups about breast cancer, I was unable to understand *fully* the extent to which this disease impinged on their lives.

Different settings bring about different responses. Being able to examine women within a variety of social contexts would have allowed for a much deeper analysis of how women cope with breast cancer. Further, those women who agreed to be

interviewed may have done so for specific reasons. Polkinghorne (1988: 170) notes that,

Narrative explanations are retrospective. They sort out the multitude of events and discussions that are connected to the launch and they select those which are significant in light of the fatal conclusion. They draw together the various episodes and action into a story that leads through a sequence of events to an ending. The story highlights the significance of particular decisions and events and their roles in the fatal outcome.

In linking Polkinghorne's words with those women who were interviewed, the following can be said: Women who volunteered their narratives may have done so because of a need to reassess their journey with breast cancer. In verbalising their past and present experiences with another person, these women may have believed that they were contributing to their own self-construction. Women were responsible for the stories they chose to put forward, the events they wanted to make known and the way in which they wanted to appear before the researcher. When experiences are selected for a listener, then a certain image is often put forward, 'We create narrative descriptions for ourselves and for others about our own past actions and we develop storied accounts that give sense to behaviour of others' (Polkinghorne: 1988:14). Based on images these women presented in the interview, it was possible for me to comment on how they coped. Yet, such an outlook of coping may not have been gained if the same women were observed in a different setting. It may well be that their behaviour in a different social setting might reflect a measure of coping not witnessed in the interview. The importance of researching women through participant observation is recognised and would have allowed for a much richer gathering of data.

### **Data Collection and the Interview Process.**

Appointments to interview women were made over the phone and interviews were conducted in women's houses. Schatzman and Strauss (1973:32) believe that a 'researcher's success depends simply on taking into account the comfort and convenience of a particular host or sub group'. Interviewing women in an environment they felt was comfortable helped them to remain focused and relaxed throughout the duration of the interview. Yet, some women seemed more relaxed than others. I felt that I could relate better to those who were in my own age category. Women in their thirties, for example, seemed to share many of my own interests. Whether it was sport, having a teaching profession, being of European descent, or studying, there seemed to be some connection that could be made. Being able to bond with these women from the onset of the interview allowed me to feel comfortable in the types of questions I could ask.

One woman, who having had her first mastectomy at thirty-one, spoke of the terror of witnessing her body for the first time following her operation. I remember thinking about my own breasts and how I would have coped. Having only been married for five months at that time, I became conscious of my own sexuality and body image. Witnessing the pain felt by young women whose breasts had been cut off, led me to ask questions about their husbands and the support they received from them. Unconsciously I also questioned my own husband and how our relationship would change if I were in the same predicament. Even though my husband tells me that he would be there to support me, I wondered about the impact of this disease on our marriage and wanted to seek possible answers from the women who I bonded with. Yet, considering my thoughts on this issue I chose not to examine whether married women coped better than single women. In hindsight, this would be a new category

that I would investigate if follow up research were to be conducted and a larger sample of women interviewed.

Interestingly I became conscious of my own body parts when interviewing women with breast cancer. This was something that I hadn't given much thought to in previous years. I found myself checking my breasts more regularly and actually went to the doctor to get a lump checked out on my leg. I had had this lump for five years and had done nothing about it. Interviewing women my own age therefore made me accountable for my own health and I realised the importance of action rather than ignorance. Thus, interacting with younger women unconsciously influenced the types of questions I asked and the confidence in which I pursued certain areas in my research.

When interviewing older women I did not feel as confident to ask certain questions. During one interview with an eighty-one year old woman for example, I was more reserved in the way I phrased my questions. Listening to Beth speak openly about the inadequate ways in which younger people deal with breast cancer made me feel that I had to be careful in the themes I chose to explore. Beth, a widow, also spoke about her sexuality in a different way as compared to the younger women I had interviewed. Beth spoke more of the need for women to accept their bodies, rather than attempt to change them through operations and breast reconstructions. Sensing a certain disapproval with the way in which younger women cope with breast cancer definitively influenced my persona in the interview process. As a result I steered away from questions of a sexual nature as I felt that I would only be intruding in Beth's personal affairs. Thus, in both these two cases mentioned, my interactions with women varied and influenced the types of responses that were received.

Prior to the interviews each of the women consented to a tape recorder being used. Interviews were later transcribed. Each interviewee has been given a pseudonym to ensure confidentiality. They are identified in this thesis only by their aliases. Names of hospitals, medical professionals, support groups and places where social gatherings took place, have not been included to protect the confidentiality of each participant.

In attempting to understand how the women in my sample cope with breast cancer and whether 'Global Faith' facilitated coping, it was important that questions outlined in the questionnaire were relatively unstructured. Women who completed the questionnaires were not given a series of answers to choose from when completing it. Rather they were asked to write written responses in a space provided. These questions, which were later reiterated in the interview, sought to encourage women to be open with their experiences. Women who completed the questionnaire and were interviewed were therefore given a chance to firstly tell their stories and how they came to find out about their illness. The main aim of this study is to understand and examine how the women I interviewed cope with breast cancer. Data pertaining to the complex relations between women's religious beliefs, the presence of global faith and their ability to cope with breast cancer is presented in a diagram retaining the complexity of the interrelationships discerned from each woman's story. Each story is examined separately and has a summary diagram at the end.

The diagram included at the end of each case study only presents the option of the presence or absence of global faith. Global faith is basically something a person has or does not. While confidence may vary more widely, global faith is either present or absent. The reason that global faith was examined in the women's stories was because from the onset of this thesis I was fascinated with the aspect of faith, more precisely how it works, who has it and the various ways in which faith can manifest

within an individual's life. During the very first year of my thesis writing I thought of writing a thesis on faith alone, yet I was unsure as to what direction I should take. Some six months into my studies, in a total state of confusion as to the precise nature of my topic, I had dinner with a family friend. We spoke about my decision to write on faith and my family friend told me of her faith whilst battling cancer. Unfortunately she and her mother were diagnosed at the same time with the same type of cancer. Her mother died two years later and she survived. It was during our discussion that I knew I wanted to write on cancer and somehow link faith into this illness.

I decided that I would research women who had breast cancer. There are some many cancers that I could have chosen, but breast cancer caught my attention. I knew that I wanted to do research for women and breast cancer was an area where I knew I could specifically focus on women's dealings with illness. Further, in linking my passion for faith with my narrowed topic, I then decided that I would look for a type global faith in the cancer stories I was presented with. In a nutshell this is how my thesis topic eventuated and the motivating factors behind my five years of research.

Another decision I made when drawing up the questions for the interviews was that I wanted faith to emerge from women's stories. I felt at the time that if women were allowed to simply tell me how they coped and the sources behind their coping, then the presence and role of faith would emerge. Further, having women tell me directly what their faith story was may have resulted in responses that were standard and rehearsed. They may have described the role of faith only because I mentioned faith. This was a mistake. I later realised when coding my data that questions more specific to women's faith or faiths could have been asked during the interviews of those women who mentioned faith. This might have clarified and pinpointed more precisely

the nature of women's experiences from a religious point of view. Further, in not asking pertinent questions during interviews, when faith appeared unclear or hazy, made the task of coding extremely problematic.

### **The role of Narrative as a Research Tool.**

As this study involves interviews of a story telling nature, it is imperative to discuss why this method of data collection was relied upon. Fundamentally, narrative is about sharing one's past with another whereby life events are ordered towards the overall configuration that is the 'self'; narratives involve a performance of some sort where human identity is shaped, reflected, embodied, produced and reproduced. Narratives are indeed a valuable tool to use in research in that they promote the sharing of intimate emotions and beliefs; narratives encourage the exchanging of knowledge and wisdom that can be interpreted by the researcher (Cortazzi 1993). The potential that narratives have in encapsulating people's sense of the world is of the utmost importance in any study involving women.

Polkinghorne (1988:119) believes that, 'people use self-stories to interpret and account for their lives. The basic dimension of human existence is temporality, and narrative transforms the mere passing away of time into a meaningful unity, the self'. Polkinghorne sees narratives as providing human beings with a source through which life events can be threaded into meaningful unified themes (1988:126). Hence in telling, listening and reflecting upon stories, the chance arises for each of us to not only share those events that make up our past, but to share the life journeys travelled by others. Further, each of us has a story to tell, a past full of events that have played a role in who we are and where we are headed. When stories are shared with others, a person's social identity is revealed. When individuals are vocal about life events, their sense of self and where they fit in the scheme of things is unveiled and made

apparent to those who listen. Oral accounts of personal experiences were invaluable in finding out how women in this study coped with breast cancer and the role of global faith in precipitating coping. Their words and gestures provided a window into how cancer has impinged on their lives; women's narratives embraced individual interpretations of breast cancer and its impact on personal and social forces.

Bauman (1984:21) sees narrative performances as mediums 'for the encoding and presentation of information about oneself in order to construct a personal and social image'. Eisner (1997:264) comments that 'narrative, when well crafted, is a spur of the imagination, and it is through our imaginative participation in the worlds that we create that we have a platform for seeing what might be called our "actual worlds" more clearly'. Narrative in this sense is seen as the study of everyday life occurrences; narrative reflects the ways in which people deal with an array of social situations.

Narratives recapitulate social and cultural expectations on human actions. Storytellers, act as shamans reaffirming the sacred space of heroic and fantastic events that encompass everyday secular lives. Langellier (1989:243) believes that 'in everyday talk, we tell stories, or personal narratives, about our experiences — the mundane happenings of an ordinary day and extraordinary events that mark our lives'. In listening to the sample of women in my research and their interpretations of coping with breast cancer, their sensitivity to certain issues to do with body image, identity, and global faith unfolded; their narratives allowed me to discover meanings attached to illness and recovery. Stories openly shared with others quite often focus on life events that are deemed significant and special. Indeed memories of past circumstances that are constantly recalled, retold and reflected upon, can be viewed as part of the process of constructing one's life, giving it shape and meaning. Yet, for many individuals their choice of words can play a major role in the interpretations

given to life experiences. According to Gubrium and Holstein (1998:64), 'personal accounts are built up from experience and actively cast in the terms of preferred vocabularies' (Sacks 1992:174). This theory is supported by Foucault (1978; 1979; 1980a; 1980b) who too believed that discourse is very much a reflection of various institutions that lay down a framework for the expression of storytelling. Consequently, researchers must be aware of the various ways in which themes can be verbalised by individuals in an attempt to portray a particular linguistic interpretation to experiences that have shaped their lives.

In examining the role of narratives within a cultural and social framework, researchers have been warned to enter into the analysis of personal stories with caution. Writers such as Bruner (1984, 1987, 1990), Gergen (1994), Gubrium and Holstein (1998) and Linde (1993) have argued that narrative as a means of expressing one's story with others is heavily influenced by social constraints that define what constitutes a story. Accordingly, the stories that people tell are shaped by a number of social expectations. In engaging in conversation about one's life, the narrator creates and constructs certain kinds of self-images in relation to the social environment. As Coffey and Atkinson (1996:61) pointed out, 'although the reported biographical events may be unique to the individual, they are structured according to socially shared conventions of reportage'. Thus, life stories are construed and constructed in relation to cultural conventions and social settings. Such aspects must be considered when analysing narratives and their place within the lives of people.

In examining the biographies of women in this study, narrative analysis is helpful in locating the presence of global faith.. Linking the stories of women interviewed results in a better understanding of the impact of breast cancer on human lives. Analysing their narratives does not simply generate new theories about how they cope with illness—narratives are also a means that serve to empower women.

Research for women by women is imperative in that it 'tries to take women's needs, interests and experiences into account and aims at being, instrumental in improving women's lives in one way or another' (Duell Klein 1983:90). The inner beliefs of women are valued in their own right; the narrative can also understand how personal experiences in relation to breast cancer are manipulated and construed by social and historical forces (Acker, *et al.* 1983). Thus, understanding the impact of breast cancer on the lives of women in this research requires that they are given the space to vocalise their experiences in their own terms with their own visions. .

If we think about the fact that the social is very much a product of communication processes, that communication itself is social and that all sociological work is based on communicative work, then narratives are the epitome of deriving social theory. Among the women interviewed in this study, narratives were used to examine the range of human experiences given to cancer. Anger, hope, anxiety and acceptance are emotions that can be understood when stories are investigated. Georgakopoulou and Goutsos (1997) believe that in addition to narratives providing an avenue whereby themes are shared and knowledge is acquired, 'narrative discourse exhibits an unquestionable primacy in our everyday social lives. Narratives not only permeate our lives in their different shapes, but also form a constitutive element of them, a fundamental principle of organising and making sense of our experiences' (p.31). Narratives have been relied upon in this study as a means of sequencing and chronologically ordering meaningful episodes. Women in this thesis spoke about notable influences in their lives that facilitated their ability to cope with cancer and drew attention to those sources that helped in their overall recovery.

### **Data Summarisation and Interpretation.**

The narratives of the women interviewed were gathered in an interactive process. However, their behavioural responses, or non-verbal responses to questions answered, were not outlined in the transcripts or the case studies that are included in this thesis. The intent of this research was to understand how the interviewees coped with breast cancer through listening to their narratives of coping. A linguistic analysis of their opinions and viewpoints was therefore not sought. Presenting the stories of women interviewed as smoothly as possible was a methodological decision that helped to focus primarily on what women had to say about their experiences with breast cancer. Choosing to concentrate on what women in this study had to say, rather than how they said it meant that stories were presented in a clear and coherent way. However, in not drawing attention to non-verbal meanings such as stumbles, or crying, or confusion in thoughts on particular issues, while enabling the focus on what was said forced a certain lack of depth or completeness to the responses documented. There has indeed been a considerable amount of research carried out on communicative events and their relevance in describing and interpreting social experiences (Atkinson et al 2001; Carter and Spitzack 1989; Cortazzi 1993; Hymes 1972). Hymes (p.290) notes that within oral narratives,

Tone, manner or spirit in which a speech act is performed, or the emotional tone of the speech event, indicated by choice of language or language variety, gesture or paralinguistic cues such as intonation, laughter, crying, make a point and transmit a message.

In retrospect, making note of observations and emotional expressions could have allowed me to understand how these women felt about certain issues with greater insight and precision. Presenting transcripts of women interviewed in a grammatically correct way, without the presence of stumbles or speech errors, has meant that their voices were somewhat stifled and silenced. However, this was done to facilitate a focus on the content of what was said.

by women in this research in their attempts to cope with breast cancer. These summaries also located the place of global faith in their recovery from illness.

### **Insights Gained from the Data**

I assumed from the onset of this thesis that everyone had faith in a God, everyone believed in a higher being, whether it was Jesus, heaven or hell. I have now come to realise that this is not the case and a person doesn't necessarily have to believe in a God to view life in an optimistic way – to have global faith. Many of the women that I interviewed relied upon a number of sources to attain peace from suffering. Therefore coping with breast cancer varies from individual to individual — what may provide sustenance and strength for one person may not for another.

When I interviewed those women with breast cancer, who did not believe in God, or Jesus, or the Holy Trinity, I was amazed to find that many still managed to view life in a sacred way. I was pleasantly surprised to find that spirituality comes in various forms and cannot easily be categorised into the one mould. My sheltered schooling, upbringing and professional career meant that I had a very limited view of the concept of spirituality and faith when I began this doctorate. My Catholic background can be attributed to the way in which I viewed faith prior to this research. As a Catholic, I was educated in Catholic schools at both the primary and secondary level. I have also spent the last seven years teaching at a Catholic College, which I have enjoyed thoroughly. Part of my professional responsibility at this school involved teaching religious education to year seven and eight students. At the centre of each lesson I taught the importance of Jesus Christ in our lives and the need to have a religious basis to govern our thoughts and actions. When teaching religious education, the syllabus required that we discuss the essentiality of divine love in our everyday existence. Lesson plans were therefore designed around the premise that

there is a need to encompass God in our lives if we are to truly feel complete within ourselves.

Meeting women who radiated a confidence in their world that wasn't necessarily tied to fundamental religious beliefs provided me with the knowledge that faith is foremost something possessed within— Faith is not necessarily dependant upon traditional ways of thinking, or The Cross, or Buddha, or Jehovah. Further, faith is not based on an intellectual assent that is governed by reading scriptures or religious texts, or going to church or saying the Hail Mary. Instead, as many of the women relayed to me through their stories and through their means of coping, faith is a feeling of trust, an emotion of global confidence in the world. Faith is something you either have or you don't. To add to this, I soon realised during the course of my studies that this kind of global faith can be achieved through numerous sources. Meditation, children, family and friends, hobbies, animals and support groups provided many of the women in this study with the confidence to go on despite adversity; such sources provided pathways to global faith that allowed half of the women in this study to deal with their illness in a positive and effective way. Even if cancer threatened the happiness and lives of the women I interviewed, global faith helped many to rise above the tragedy of their situation and make the most of their time on earth.

An interesting category to emerge from the data, which was totally unexpected, was that most of the women spoke about becoming more selfish with their time. Many of the women expressed a desire to be more selective with their energy once diagnosed with breast cancer. This often meant discarding that which brought them unhappiness or sadness and finding that which provided relief and comfort from their illness. Adopting a totally different attitude to day-to-day living, as a means of coping with a life threatening illness, was not something I had anticipated finding. I simply thought that if a person had faith then that was all that mattered and coping would be

easy. However, as I soon found out all of the women in some way or another, changed their lifestyles and attitudes to areas such as friends, work, family, death and illness. Hiring a fitness trainer, spending more time with friends, attending yoga and meditation classes, were just a few life changes that are outlined in the following chapter. The next section therefore draws attention to the fact that coping takes various forms and does not always embrace a belief in the divine or the holy. Coping through relying on a pet, or going out with a sister, or mother, or receiving sound medical advice from a doctor or social worker, worked just as effectively to soothe sensitive nerves and pessimistic outlooks.

### **New Areas For Research.**

In the narratives that follow rarely was their talk of the damaging effects that support groups could have on recovery from illness. This may be partly attributed to the fact that women who agreed to partake in the study regularly attended support groups because this helped them to address certain issues tied to illness. Women, who had dropped out were not sought by co-ordinators as an option for interviewing. Had I have been given the opportunity to speak to women who had ceased attending support groups, then a different insight into coping could have been achieved.

Negative effects that religion, faith or spirituality can have on coping is a theme that has not been addressed in this thesis. This thesis chose to examine how women cope with breast cancer and those sources that play a pivotal role in dealing with illness. Thus, questions asked in the interviews and questionnaires did not directly target support networks that can cause distress or ill content when battling a life threatening disease.

## **Conclusion.**

This chapter has drawn attention to the various research methods relied upon in this thesis. Understanding the role of narrative as a means of approaching, understanding and explaining how women in this study cope with breast cancer is a major concern. Recognising the special importance of narrative as a mode of communication is essential if light is to be shed on women's experiences with illness. Giving participants the space and freedom to verbalise their thoughts in their own words and granting interviewees the right to interpret and account for their own feelings is imperative in the writing that follows.

## **Chapter Seven: Women's Stories: How Women Cope with Breast Cancer and the Role of Global Faith.**

### **Introduction.**

This chapter examines how the women in this study cope with breast cancer. It also investigates what these women have to say about notions of the sacred, the divine, God and religion. The importance of such forces in their road to recovery and their ability to manage illness through relating to transcendental forces are identified. The notion of global faith is also traced with a view to understanding its place in the coping process and its ability to encourage functional behaviour.

The qualitative nature of the data presented is rich and dense. In order to remain faithful to the individuality of each story, women's stories are presented singularly. Allowing women's narratives the space to be firstly read alone, without the overall dissection of integral themes and categories, draws attention to the fluidity of their inner voices.

Twenty stories are presented in this section. Each story begins with a précis. This is followed by a general summary of what each woman has to say about her experiences with breast cancer. Following this, coping strategies that emerge from the narratives are identified and discussed. At the end of each story there appears a diagram that traces facilitators to coping and factors that assist functioning in a productive way. Line numbers are placed in brackets in each of the diagrams. These numbers may be referred to in the full transcripts that are listed in appendix 7.1.

## Women's Stories.

### Belinda's Story.

*Belinda is forty-five years old. She is married and has three boys. Belinda discovered a lump in her breast in 1997. In February 1997 she had her first mastectomy. Two years from that day she had her second mastectomy. In May 2000 Belinda experienced 'funny sensations' in her head. After a series of check-ups she was told that she had two brain tumors. It was during a MRI that her doctor also found five little tumors in her brain. Belinda has received extensive treatment involving high doses of chemotherapy and radiotherapy. For four years in a row, Belinda has lost her hair. Belinda remains positive about her terminal condition.*

Belinda discusses the importance of her work and her strong Christian beliefs in her battle with cancer. Belinda has worked as a Salvation Army Officer for approximately twenty years and constantly draws upon the doctrines she preaches to others. Here Belinda describes how God helps her to deal with pain and suffering,

I was forty when I got it. All the different things that have happened to me to prepare me for this. I have been a Salvation Army Officer for nearly twenty years now and all the things I have learnt during that time, all the times I preached, I mean I was preaching to myself too so that I had this incredibly strong foundation when it came and I think it has been like a gift to me and what I say is that when things get tough and they are bound to sometime, you have something to fall back on. (L: 3017-3024)

Attending a support group on a weekly basis helps Belinda to deal with the uncertainties of her illness and the possibility of her dying. Belinda appreciates belonging to a group and being able to listen to the stories of other women. In being able to see how other women cope successfully with breast cancer, Belinda is given hope and encouragement. We see this when she says,

What happened when I joined this group was that I walked in the door and met ladies who lived with cancer and that was a really good thing because at the time I was thinking how long do I have to live? I remember sitting here on Christmas day of that year after I had my nodes removed. All my brothers and sisters were singing carols and praying together and I just looked at them and I wanted to say, "Hang on to this as this might be the last year it will be like this". I had to go out and cry, but I didn't tell them. I had no idea anyway and assumed that everyone who gets secondary breast cancer dies. So when I walked into the room and found out all the ladies' stories I was blown away and

realised that people live with this thing and move on. And it has been a really really good thing for relationships and support. (L: 3033-3043)

Belinda regularly has lunch with women she has met in the group and speaks to them on the phone whilst in hospital or receiving treatment. Not only has the establishment of new friendships been important for Belinda, but also the insight she has received from attending the group. Belinda believes that her recovery is assisted through being educated about treatments, what cancer is and the types of questions she should ask doctors. Prior to her diagnosis with breast cancer, Belinda states that she was intimidated by medical professionals and would not have dared to question the decisions they made. However, Belinda has adopted a more self-directed stance towards treatment. She now chooses to be assertive when she is not happy with a doctor's approach to her recovery. Belinda comments on the benefits of her support group in interacting with medical professionals,

What it really freed me up to do is to go to the doctor and ask questions that in the past I would never have thought of asking. I probably wouldn't have had the courage to and to also be quite assertive and say, "No I don't want that and yes I want that and will you do this before that?" I really found that to be freeing and it has also given me courage. And the other reason is that sense of assertiveness. I have always been a peacemaker and I am by nature a peacemaker. I use to avoid conflict, but now I am willing if I need to be up front. When you have an operation for a brain tumor they sometimes cut your jaw and I had no idea till I woke up and thought they had pulled out every tooth out of my right side. I couldn't eat for a couple of days. And the next day they gave me this piece of paper all typed up to say that in the operation I had my jaw muscles cut and these are the exercises to do and I thought why didn't they tell me? When the surgeon came to see I said to the doctor, "Please don't take this as a criticism but I am the sort of person who would rather know everything that is going to happen beforehand so that I know what I am going to be up for. I know that some people don't want to know anything and that makes it hard for you, but if you supply me with a piece of paper regarding my jaw it must happen more than once. It wasn't something you found you had to do to me. I am just wondering if you could let people know that that might be the case. Then when you come out of that awful operation you understand why you're feeling the way you feel". And he said, "Yeah that's true I take your point we should tell people and it would make it easier for them". Three years ago I would go to the doctors and say yes sir, no sir, three bags full sir. Anything they told me to do I would do. I would never challenge, never question because doctors are doctors they know everything, but now I don't agree with that. (L: 3049-3073)

There are a number of factors facilitating coping in Belinda's story. Belinda's work is pivotal in her ability to cope with not only her breast cancer, but also her brain tumors. Her experience in 'preaching to herself while preaching to others', is seen to have provided the framework for her own coping with dying. Through her role as a Salvation Army Officer, Belinda feels she has acquired the necessary skills to view her illness in a positive way. Further, her trust and global confidence in the universe and her belief that life does not end with the dying process, allows her to feel safe. When the time comes to die, Belinda believes she will be 'carried along'. This belief has empowered her to cope with her illness. Coping enables her to function productively.

Belinda uses her role as an Army Officer to make sense of her situation. Belinda draws meaning from her work and her religious beliefs. Through this meaning she reaches a state of confidence and trust in a higher being and is able to reach a level of global faith. Outcomes of her global faith are that she no longer fears the threat of dying. Her dying is something to be reflected upon, rather than shunned,

Underlying all my life over a period of time I have built up a philosophy of life that God is interested, has my best interest at heart and it is an eternal interest and not just an earthly one. This interest is not going to stop once I die and it is not just attached to my illness. (2996-2999)

In trusting that her existence is not just earthly, but also eternal, Belinda is able to accept the possibility of dying. In believing that there is a greater force that is ultimately in control of her life, Belinda is comforted. We see here a direct relation between global faith and the ability to be brave and confident about her terminal illness. Confidence in a transcendental force gives her hope that she will be watched over by a Supreme Being. This is seen when Belinda states, 'On the whole I suppose it is truly my faith and this underlying belief that God knows what he is doing and is in control. This knowledge keeps me going' (L: 3126-3128). In being able to rely on a

The time taken to interview women ranged from one to two hours. Transcriptions of interviews varied in length, some reaching five thousand words, whilst others only one thousand words. Interviews in full have been placed in appendix 7.1. Each line in the interview has been given a specific number. These numbers are referred to in the data chapter when supporting theory with evidence. Listed below is an example of this technique,

- 1 F: Six and a half years ago I was diagnosed with breast cancer. In the beginning I
- 2 was in shock and it lasted months. I was fine in hospital. All the visitors came in
- 3 and with all the flowers and all the attention of the world around you, you didn't
- 4 have time to come to grips with cancer. This was because it was probably the last
- 5 thing in the world that I thought would ever happen to me and that's the problem
- 6 with illness you never think it is going to happen to you.

The response of a participant is represented with the initial of her fictitious name. The initial of my name is represented in *Italics*. At the beginning of each story there is a *précis* that is highlighted in *Italics*. The *précis* serves to give a brief background of each of the women and includes information such as age, the stage of recovery and whether or not family members are present in their lives.

Locating relevant themes that were linked to the answering of questions asked at the beginning of this study was crucial in the construction of an understanding of how each woman coped with breast cancer. Considering the length of many of the interviews, coding and finding themes in the data required extensive work. Sifting through women's transcripts required that I not only remained faithful to each of the stories presented, but that I also made connections with over-riding themes that stemmed from the data. Trying to find this balance is best summarised by Atkinson, (cited in Strauss and Corbin 1990: 117),

This aspect — making it all come together — is one of the most difficult things of all, isn't it? Quite apart from actually achieving it, it is hard to inject the right mix of (a) faith that it can and will be achieved; (b) recognition that it has to be worked at, and isn't based on romantic inspirations; (c) that it isn't like a

solution to a puzzle or math problem, but has to be created, (d) that you can't always pack everything into one version

Ensuring that I did not 'pack everything into one version' was important during the stage of data analysis. Whilst commonalities existed with what the women in this sample said about coping with breast cancer, it was important to present their narratives in a unique and truthful way. Sarbin (1986) comments on the importance of maintaining a participant's self-identity in the interview. Sarbin explains that a participant's 'particular social identity is being claimed' (p.243) in the analysis of data and that 'everything said functions to express, confirm, and validate this claimed identity' (*ibid*). Ensuring that a participant's identity is recognised safeguards the researcher from making general assumptions. Being aware of the cultural and social idiosyncrasies of each story, of each individual studied, is imperative if an accurate framework of meaning is to be achieved. In order to remain true to the voices of the women who spoke about their individual experiences with breast cancer, each story is examined separately in the next chapter. Presenting personal encounters with breast cancer as first-person narratives initiated a sense of 'belonging' and 'identity' to stories and their tellers; presenting the stories of these women as separate entities highlighted the intricate thoughts and beliefs attached to each of the participants.

### **Identifying the Story.**

Considering the lengthy nature of many of the interviews it was important that key themes were identified and presented in a summary format. Presenting a coherent and plausible account of key factors that contributed to coping with breast cancer and examining the role of global faith required skill and judgement. Further, as Polkinghorne (1988:160) asserts, 'narrative meaning consists of more than the events alone; it consists of the significance these events have for the narrator in relation to a particular theme'. Bearing this in mind, the summary attempted to

encapsulate not only relevant themes pertinent to the study at hand, but also how the world was perceived from the point of view of a breast cancer sufferer.

Singleton (2000) develops a style 'for representing stories in a condensed form' (p.38). Singleton refers to this style as a 'paraphrase', a 'shorthand story' that attempts to capture the most valuable parts of a narrative (p.38). His style, which he attributes to summary techniques relied upon by Atkinson (1990), Cohan and Shires (1988) and Polanyi (1985), is effective in drawing together important and meaningful experiences. I have adapted his approach in the development of the complex diagrams used to summarise the interrelationships of the factors related to coping.

When formulating my own summaries representative of women's stories in this study, the aim was to describe and detail how these women coped with illness. Being able to capture and effectively 'paraphrase' their thoughts on relevant themes was a key objective. Encompassing the variety of emotions breast cancer brings to the human spirit was important. Individuals faced with breast cancer almost always feel a betrayal of one's body. A life threatening disease such as breast cancer can play an enormous role in destroying a woman's sense of spirit, physical attractiveness and sexuality. The individual, who must deal with a deadly illness, commonly encounters other feelings such as shock, anger, jealousy and despair. As described by Kleinman (1988), when a person is faced with cancer,

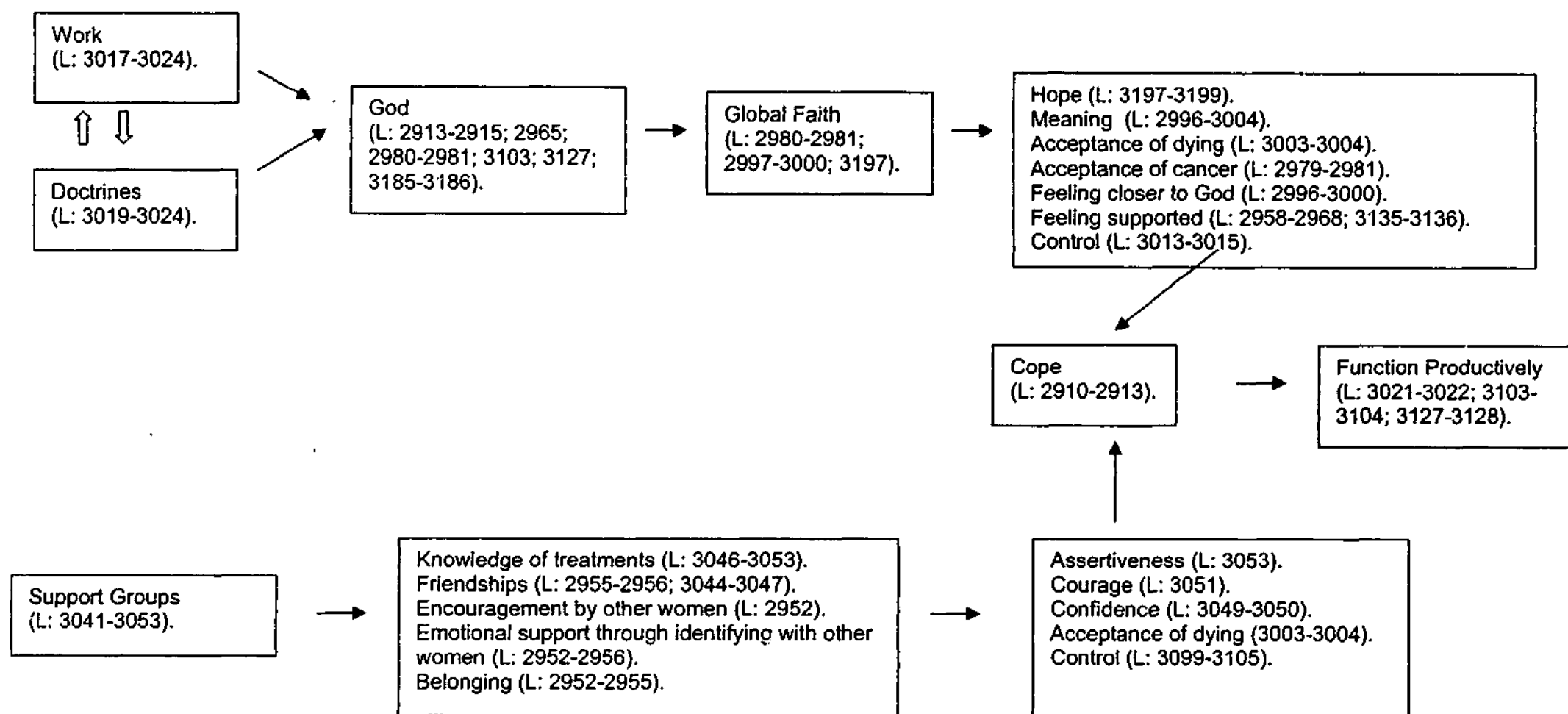
A closely related feeling is grief and wretchedness over loss of health, a mourning for the bodily foundation of daily behaviour and self-confidence...Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. (p.45).

Most importantly how a woman reacts to breast cancer is also dependent upon her image of her body, her conception of what cancer means and her ability to take control of the situation at hand. My summaries drew attention to sources relied upon

cosmic power, the world is seen to be a friendly place and anger and vulnerability cease to exist.

Attending a support group helps Belinda to cope in a number of ways. Belinda feels more assertive with medical professionals. She is now able to ask surgeons questions pertaining to her treatment without feeling intimidated. As a result, Belinda feels in control of her recovery and this helps her to function productively. The support group is also a place where she is able to interact with other women who have terminal cancer. Witnessing their positive attitudes and their ability to 'move on' inspires Belinda to view her illness in a similar way. Friendships are established in this group, which provides Belinda with a network of support, love and care. Belinda is able to cope and make sense of negative thoughts in the process, which helps her to view her illness in a confident light. Global faith is not present here. Her support group provides her with a direct link to courage and bravery in the face of suffering. This can be seen in diagram 7.1 below.

Diagram 7.1



### **Debra's Story.**

*Debra was diagnosed with breast cancer in December 1996. She was thirty-five at the time. As a result of cancer, Debra had a mastectomy, but has since had a breast implant. Debra experienced severe side effects when undergoing chemotherapy, one of these being the onset of menopause. Debra is divorced and has two children. She is currently in a relationship with a man twelve years her junior. Debra doesn't like the word remission, rather she sees herself as 'cured'.*

Debra sees her breast cancer as being a positive experience. Debra spoke of the changes in her outlook to life as a result of being faced with a life threatening disease. Many women that I interviewed commented on how cancer makes them appreciate the simple things in life. In Debra's case watching birds on her front lawn gives her a tremendous feeling of joy and satisfaction. Her heightened sense of perception, as she sees it, enables her to view her world in a special and unique way. Being with nature in this sense has provided a gateway to a flood of emotions. Observing nature facilitates a feeling of warmth and enthusiasm within Debra. In perceiving the world to be a harmonious and sacred place, Debra is happy and is able to view her surroundings in a special way. Simple pleasures are denoted through a connection with nature. Debra explains,

In a lot of ways I am glad I had cancer. I don't think cancer necessarily changes your life for the worst. I think you get a lot out of it, you learn a lot about yourself, you learn to appreciate life a lot more. I feel lucky in a lot of ways. I can sit in a backyard and watch the birds in the sunshine and I am so happy. I take pictures of magpies on the front lawn. The kids come home and they think I am off my tree. Things like that make me so happy because I can feel it more than other people and I would never have had those feelings if I didn't have breast cancer. Even my wedding day, that was great, but the feeling of watching the magpies, that's different. Everything is heightened. When I first got married we had to own our own house. We had to have a boat and a caravan and a car. We had all that and it was really important and now it is not. Materials aren't important. I don't have to have a flash car and a new lounge suite. Other things make me happy. It is not all bad having cancer. (L: 1943-1954)

Debra also spoke about the importance of her children during her ordeal with breast cancer. This was a theme commonly expressed by the majority of mothers interviewed.

In Debra's case her children were seen to be a motivating factor for her wanting to recover from her illness; Debra's children facilitated a will to live,

When I was going through cancer that was really hard. You know what kept me going, the kids. I had to get up, get their breakfast and take them to school. I wanted to be there for them in case I died. I wanted them to have those memories of me, of mum making me breakfast and of mum driving me to school. I didn't have a lot of energy to do stuff. Because I never had a father and that was hard as a child. I knew how hard it was not having a father and I knew how horrific it would be not having a mother and I didn't want to do that to them. I wanted them to have their mother and I would have fought to be with them, taken any drugs even if I would only have been around for another six months. All this was very important. (L: 1958-1966)

The need to have something to hold on to when death is lurking can help to soothe fears of the dying process. Debra was able to come to terms with the threat of dying through her prayers and church attendance. Debra believes that since her diagnosis she is more religious and relies upon religion for support and strength,

I think you have to get yourself through for whatever reason. I did pray. I am more religious now than before, but I am still not very religious. I did pray when I went to church and felt someone was listening to me. I really think I would become more religious if it (cancer) came back. I don't know why, I can't explain it but I found more of a need to go to church when I was sick. Whether it was just peacefulness when I was at church I don't know. (L: 1993-1998)

Participating in social events with other victims of breast cancer helps Debra to cope. Debra participated in a fundraiser called, 'Relay for Life'.<sup>18</sup> It was during the survivor's lap that Debra felt she truly connected to other cancer survivors who walked with her. Debra reflects on this event as a time to remember those who had died and the families who were left behind. Debra explains how she felt on this day,

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<sup>18</sup> Relay for Life is an event when individuals are able to come together in a team event to raise money for cancer research. Members walk around a track and are sponsored for each lap they complete. The opening lap of Relay for Life is dedicated to cancer survivors. Participants wear different colour sashes representing their relationship with cancer. Pink sashes represent a survivor of cancer whilst other colours such as a green sash signify being a carer of someone who has had cancer.

Walking the survivor's lap was very emotional. I tried to explain it to some of the women at the support group how I felt. And a lot of those people there have had all sorts of cancer. It is great that when you are on the track you wear pink sashes. Pink sashes identify who the survivors are. You really feel a bond with them, those people walking around the track with no hair. I always think of the people who are not there. I quite often talk to my friends in my head. I really enjoy being involved in it all. I always cry at these events. I am not a really soft person but I cry for the people I have known, their kids, their partners, what they have left behind. When we have our meetings, we all hug and kiss. You know what they are feeling and where they are going and what their fears are. (L: 1882-1891)

In walking the survivor's lap with other survivors of cancer, Debra is united with those who share her pain.

Debra also spoke about the importance of attending a support group. Being involved in a support group, primarily aimed at women under forty-five years, allows Debra to feel a bond with younger women facing similar problems. Debra had no support whilst receiving chemotherapy treatment and felt very alone. It was only through attending a support group that she was able to share her suffering and realise that other women also experienced similar uncertainties. These sentiments are expressed in the following passage,

I had no support at all through chemo. My surgeon gave me my chemo, which meant I had no contact with others going through chemo. So I went through twelve months of hell on my own without being able to say to someone else, "Do you feel like this? Have you encountered these emotions? Are you worried about this?" (L: 1973-1977).... Friends my age aren't going through menopause and to talk about hot flushes and sweats and feeling like your fifty, they don't really understand. Once I joined a support group I was ringing a lot of people who could understand. Listening to other people makes me feel good, especially when I am able to help others. But, I also feel that these people will be there if there is a reoccurrence and that is peace of mind. Another support group I go to has women with advanced breast cancer who are dying. You leave there feeling so lucky that you are not in their situation, but you also know that if you ever get to that stage they will be there for you and that is very comforting. (L: 1981-1989)

A number of facilitators to coping can be identified in Debra's story. Support groups directly link her to a number of coping strategies. Debra is able to listen to the stories of

other women who understand what it means to battle illness. Women in her support group understand problems associated with issues such as chemotherapy treatment and can offer her advice on the best way to manage her pain. Being able to share her experience of breast cancer with other women also allows Debra to feel that she is helping women to cope with their illness. Further, listening to the stories of dying women comforts Debra in the event of her cancer returning. This knowledge also helps to ease her fears of facing a terminal illness on her own.

There is no evidence of global faith that emerges from Debra's participation in a support group; there is no evidence of global faith in Debra's involvement in fundraisers. Debra's support group provides her with the necessary skills to cope with cancer and it is here that she can ask questions pertaining to treatment. Further, in the event of her illness returning and becoming terminal, Debra feels reassured that she would receive the best care. Such thoughts allow her to cope and maintain a hopeful outlook to life. The fundraiser serves to offer Debra a place where she can connect with other cancer survivors and their families. Here she is able to identify with those individuals who have also experienced cancer in their lives. Debra also receives recognition for her own battle fought and won. In witnessing others who are in remission, or are currently fighting the disease, Debra feels united in her journey. Such an outlook helps her to cope and feel proud of her accomplishments.

Debra's prayers can be linked to global faith. While at church, Debra prayed to a higher being asking that she be carried along during the moment of her death. By becoming more religious Debra feels reassured that a sacred force will be there to give her support in the event of dying. In having a divine power to depend upon, Debra feels that she is no longer alone in her plight with cancer. We see this when she states,

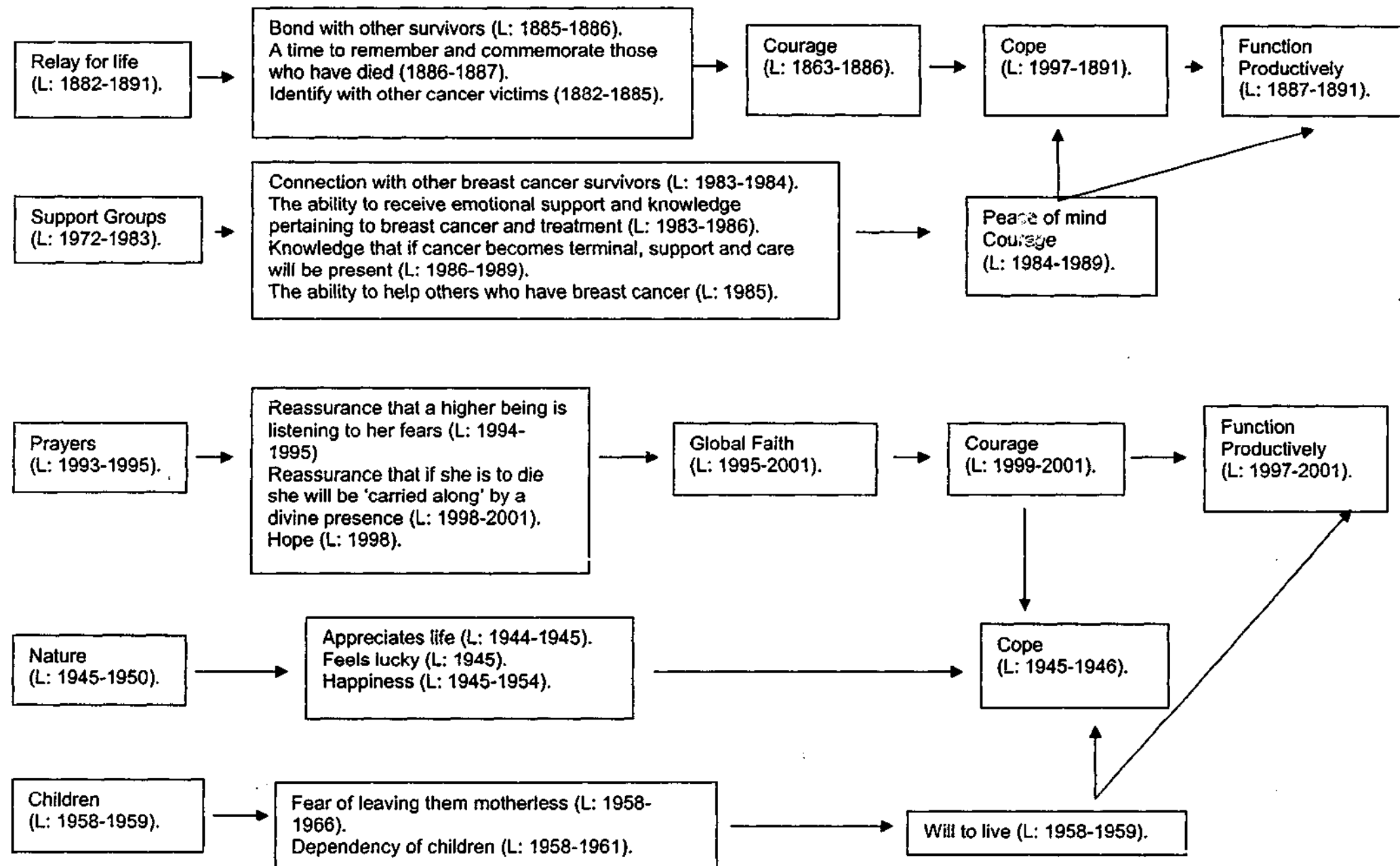
Maybe it is a hope, maybe it is something to cling to and if I am going to die. I need to have something to help me through it to think well I am going there and I will be fine. Maybe that's what it is maybe you need something to hold on to. (L: 1998-2001)

In being confident that a holy presence would be there to walk alongside her in her hour of need, Debra has hope. In depending on a sacred source for hope, Debra has global faith. Confidence and commitment are two aspects of global faith that are able to generate outcomes. In having global faith, Debra is comforted with the knowledge that she is being looked after. In relying upon a sacred force to listen to her fears, Debra feels safe and secure. This knowledge helps her to cope and function in a productive way.

Debra's children directly facilitate a will to live. Her fears of leaving them motherless and not being able to care for them generate a desire to survive. This will to live is not linked to global faith. Her children give her the courage to fight and her role as a mother fuels her desire to stay alive.

Nature is a source of enchantment for Debra. In watching the magpies on her front lawn, Debra experiences a sense of great joy and happiness. During such times she appreciates her life and the beauty that surrounds her and she feels 'lucky' that she can sit in the sunshine and take in the splendour of the moment (L: 1945-1947). Debra attributes having cancer to adopting a new view of life and it is this outlook that provides her with joy. Such emotions help her to cope and appreciate her life, yet they cannot be attributed to global faith. Nature directly precipitates positive feelings that enhance her willingness to find beauty in her surroundings. Such moments allow her to function in a productive way. Diagram 7.2 traces coping facilitators that assist Debra in her battle with breast cancer.

Diagram 7.2.



### **Grace's Story.**

*Grace was forty-six when she was told she had breast cancer. She was diagnosed in December 1998 and underwent a partial mastectomy. Grace has a twenty-two year old son and has been married for twenty-eight years. Grace is currently in remission and sees her cancer as 'a gift' and an experience that was 'one of the best times' in her life.*

When Grace reflects upon her breast cancer she says the following,

Happiness comes to mind when I think about my time with breast cancer. There is no sadness; there is no grieving, no anger. Breast cancer was just a beautiful experience. I found God in me for the first time for those three weeks. Even my mother said, "There is something about you". She noticed the change, but she couldn't understand. I have learnt acceptance. I accept my breast, I accept my past. I showed the scar to my mum and she said, "Oh that doesn't look too good". I didn't mind, she was the one with the problem, not me. (L: 2060-2066)

Of the twenty women interviewed, Grace was the only woman to use the word 'beautiful' in reference to her illness. Grace attributes this feeling to her finding God through her illness. She explains,

I was brought up a Catholic. Church at the time didn't give me anything. Early in my teenage years I stopped believing. Then at forty-six I was diagnosed with breast cancer and there was a renewal of faith. I believe if I hadn't had cancer I wouldn't have found God, found inner peace. I do meditation, yoga and tai chi. If this is done properly you get a lot of energy through your body. (L: 2085-2089)

Grace reports that since her experience with cancer she has become a lot more spiritual. Her spirituality is what has given her the strength to view her illness in a positive way. Through becoming a vegetarian, Grace also feels that she is able to regulate any negative energy that may be entering her body. She asserts,

When I started Raj Yoga, within six months I became a vegetarian. You meditate and your body says to you I don't want to eat meat any more. Meat is an animal fat and also because the animal has been killed and the energy stays in the animal and the bad karma enters into you once you eat meat (L: 2092-2096). Spirituality is not about the psychological side of things, but also about the nutritional side. The food I eat is now very important in my life. (L: 2098-2099)

Grace's story pinpoints how traumatic experiences can not only draw people closer to God, but can also encourage them to adopt a different lifestyle. In not eating meat Grace

believes that she is contributing to the spiritual well-being of her body. In practicing meditation, yoga and tai chi, Grace also feels that she is able to connect with God and her inner being. Through her spirituality Grace is able to deal with and overcome negative emotions. This can be seen in the following passage,

Yoga taught me control and self-discipline. These skills helped me with my problems in the past. I am now peaceful. We do a lot of meditation at the centre; we do a lot of healing and forgiving. You mentally picture the person from a view and whatever emotions you have towards them you let them go. They teach us about the virtues within, anger, jealousy; they teach you how to let these destructive emotions go. You learn so much about yourself and you look at life differently. (L: 2040-2045)

Grace's capacity to look at life differently through her meditation enables her to accept and deal with destructive feelings within. In this case meditation is a facilitator of faith as it leads her to a state of existing that lets go of pain and suffering; through meditation Grace re-evaluates the world she lives in and comes to a place where materialistic things are no longer valued,

Before I had cancer I was so materialistic; I was an empty shell and I was so unhappy. Now I have to drag myself to go shopping. Now I feel I give more without expecting something back in return. (L: 2075-2077)

Grace no longer defines herself according to wealth or status. Instead through the spiritual rituals she performs she is able to reach a transcendental plane where she feels safe and happy.

There are a number of factors that facilitate Grace's ability to cope with cancer, one of these being global faith. Grace's trust and belief in God also allows her to move into a state of global faith. Grace depends upon a higher being in her life to feel bright about her future. Her positive outlook to life is strengthened through the various activities she performs. Further, through her rituals she is able to reach a state of existence where she views the world in a confident way. When Grace explains the importance of God in her life she does so by using words such as 'inner peace' and 'harmony'. Grace views her

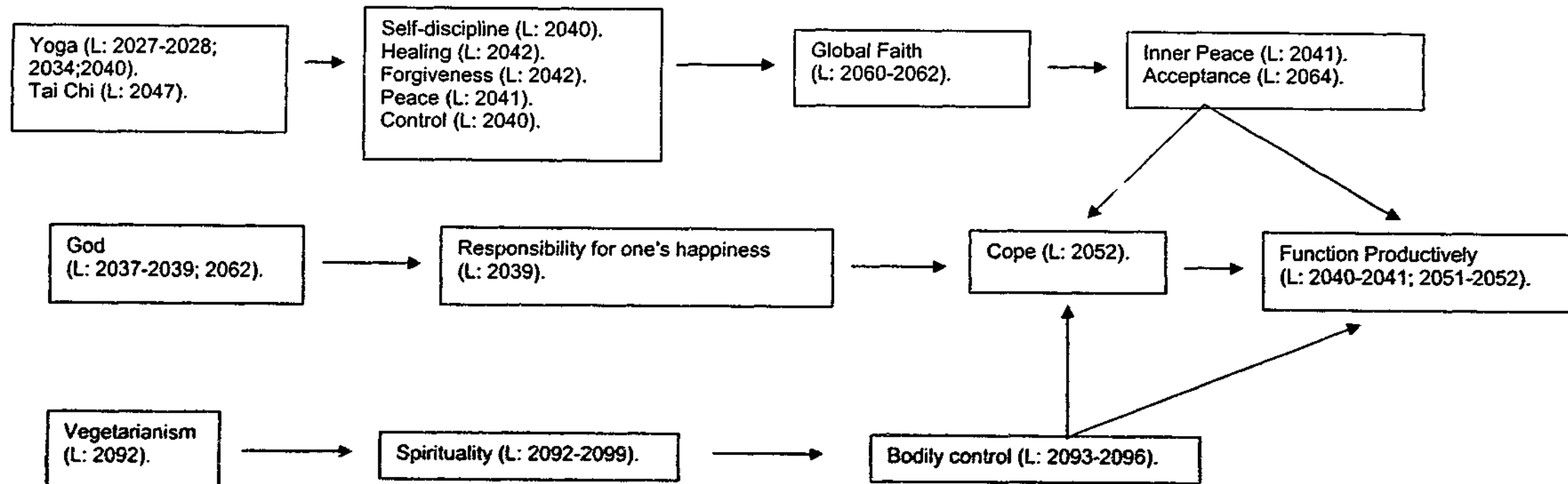
time with cancer as a 'beautiful time' that ultimately connected her to God. This is seen in the following statement,

People can look at me and see me as a victim because I had breast cancer. I am not a victim, I am proud of it and I am pleased I went through it. It has been a beautiful experience and people look at me and say how can it have been a beautiful experience. It has been wonderful because it has brought me closer to God; cancer forced me to cope with my fears. Cancer has been positive! (L: 2048-2052)

Yoga, meditation and tai chi, facilitate a core optimism in Grace's internal and external surroundings. The skills that she has learnt from practising these rituals have allowed her to deal with problems in her life. As a result, she states, 'I am now peaceful'. In being able to come to terms with destructive emotions Grace is able to, 'look at life differently' (L: 2041- 2045). The ability to view her life in a positive and optimistic way, in the face of suffering, is a characteristic of global faith.

Grace's believes that a change in diet has also connected her to a spiritual state of existing. In no longer eating meat, Grace believes she is minimising the amount of negative energy that enters into her body. Grace's decision to regulate her diet precipitates a sense of bodily control. Coping results and this empowers her to function productively. Diagram 7.3 examines the interaction of global faith in Grace's narrative.

Diagram 7.3



### **Rachel's Story.**

*Rachel is thirty-four years old and is married. She has two young children; a boy aged one year and a daughter who is four years old. She was diagnosed with breast cancer in 1999. When interviewed she had just finished treatment, this being radiotherapy on one of her breasts. Rachel is currently in remission and has a positive outlook to her recovery. As a result of breast cancer, Rachel has only one breast.*

During times when Rachel feels threatened, or in pain, her daughter comforts her. A simple hug from her daughter, or words of love, remind Rachel of her need to get better for the sake of her children. She explains,

*Sometimes I sit around in self-pity and cry and use the expression that I have bad hair days. But I will sit around in my pj's all day and not have a shower and feel really sorry for myself. That's why I thank God for my kids because my daughter comes into my bedroom every morning and says she loves me. That makes me think I have to be bright and happy today because I don't want to walk around crying. I mean some days my daughter says to me, "Why are you sad?" I know that I have to get better for her. So I try to remain positive. (L: 1586-1592)*

The worst fear outlined by those mothers interviewed, who had young children, was leaving their children motherless. Rachel shares this fear and this leads her to pray at night, 'Now I pray I will be around for my kids...I'm going to cry. I pray that I'll be around for my kids for a long time' (L: 1680-1681). This statement indicates that Rachel's prayers empower her to fight her illness. In praying to God at night Rachel displays trust in a higher being.

Rachel's husband and family are overwhelming factors that give her courage and a will to live. When speaking of the support she has received from her sister and in-laws she tells me,

*It was tremendous. I think the day after I got told my sister was at the anti-cancer council getting information on breast cancer. She would come home with a thick folder for me. She was a wealth of information (L: 1539-1541). Having cancer has brought my sister and I much closer. She would go to the library and borrow me books. And when I ended up in hospital she came in and told me everything would be fine. The day I rang her on my mobile, when I was first diagnosed, I walked in the door and she said, "We will help you!" She is my guardian angel. She is younger. She comes around and takes my kids out while I am on chemo and*

having a rough cycle, or she will come here and clean my house. I don't know how people cope by themselves who haven't got a family, or anything like that. Yeah the whole family has been really good (L: 1545-1553). My in-laws have been really good. They minded my kids for out-patient appointments. They have met me at the hospital and taken the kids to the cafeteria if they have had to. It is good to have a good family. (L: 1614-1617)

Having family to rely upon helps Rachel in her battle with cancer.

There are a number of factors that facilitate Rachel's ability to cope. Rachel's family and husband precipitate a feeling of support and love, which encourages her to go on despite the uncertainty of her illness. Her sister, who is a nurse, is able to provide her with knowledge about cancer and this assists her coping. Rachel's in-laws are also there for her when she needs someone to watch over her children, as is often the case when cancer treatment is involved. Having close family members to rely on assures Rachel that she has people to depend upon during times of need. In this instance there is no evidence of global faith. Rachel's bravery emerges from her dependence upon external sources. These sources provide her with the courage to face her illness in a constructive way.

Global faith involves the handing over of power to a greater force. Rachel's act of praying each night tells us that she depends upon a higher being to watch over her and protect her (L: 1680-1681). Her trust in this sacred force — her global faith, helps Rachel to function in a productive way; Rachel is able to let go of her anxieties associated with dying. The ability to feel a sense of hope, a belief that things will turn out fine, that she will survive, facilitates an optimistic outlook to recovery. In remaining positive Rachel is able to function in a productive way. Rachel's sense of 'connectedness' with a higher being (L: 1685) allows her to unburden her fears and anxieties associated with cancer.

Through her prayers and trust in God, Rachel is able to reach a sense of global cosmic confidence in her surrounding environment. We see this when she states, 'Yeah my faith is stronger now. I pray every night before I go to bed; I pray that I will get through this (L: 1675-1676)...I hope he is listening. I feel more connected to him now' (L: 1685). Rachel prays to survive for the sake of her children. In praying to a transcendental force Rachel is confident that a greater power will help her to face the uncertainty of her future; it is this confidence that is the source of her courage. Courage thus comes from global faith.

Rachel relies on her daughter to be 'bright' and 'happy' and her daughter relies on her mother to feel that everything is fine. We see this in Rachel's story when she says, 'I have to be bright and happy today...I know that I have to get better for her. So I try to remain positive' (L: 1589-1592). Rachel's interest in her daughter's well-being gives her the power to face her suffering. Her daughter is the reason why she gets out of bed and is able to face the day ahead. When Rachel first told her mother of her illness, she commented on her need to be strong for her children,

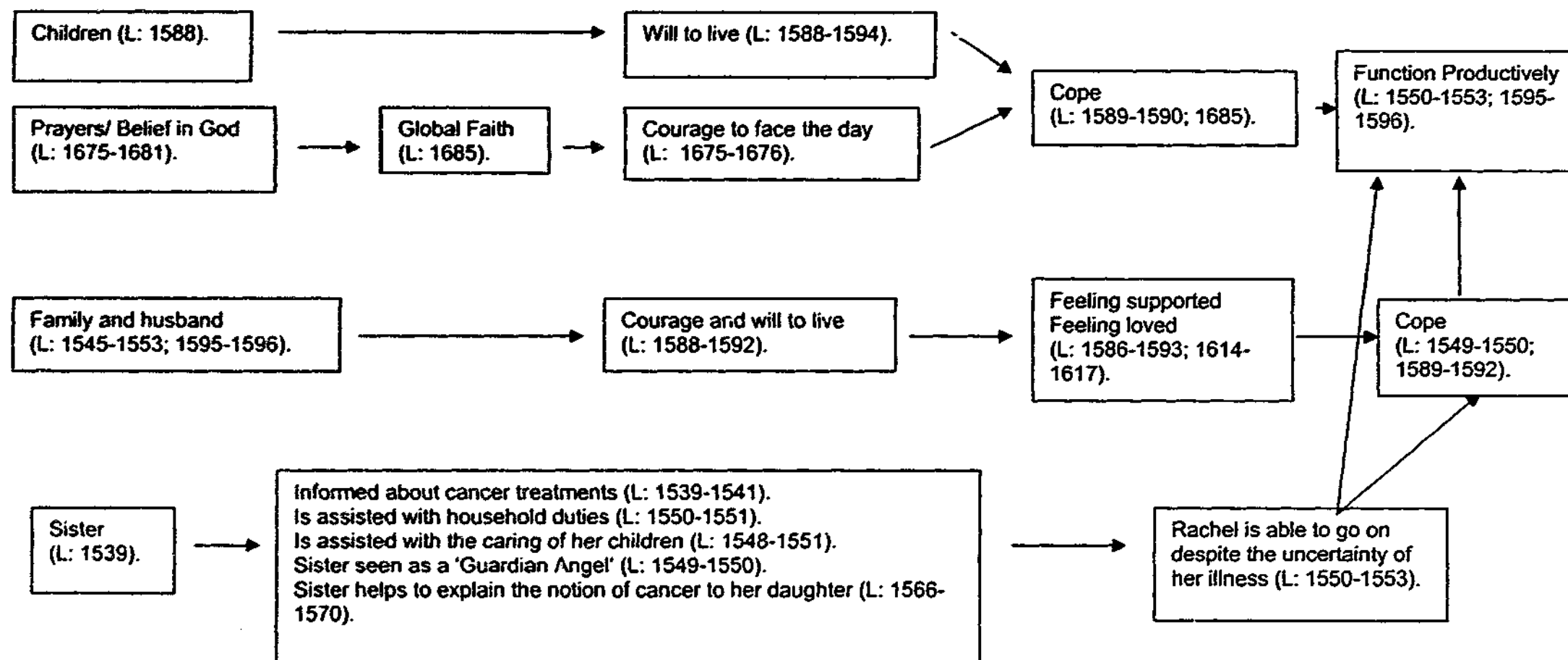
I remember when I first told my mother of the diagnosis. She fell apart and I told her not to cry because I wanted everyone to be strong for my kids. Not mainly for me, but for my kids. I mean when you have kids they always come first. I said to my husband as soon as I walked out of the hospital, "You have to be strong no matter what happens, you have to be strong for our kids". (L: 1520-1524)

Rachel's daughter also relies on her mother to feel safe in her own world. Rachel reflects on her determination to survive for the sake of her children in the following way,

Everyone says, "Oh you're just so positive". Like I said from the start I wasn't going to let this thing beat me. They could inflict whatever drugs they wanted into my body as long as I am around for my kids. I can live without a boob and I can live without looking sexy at the pool. I have the love of my kids and my husband and my family and that's all that matters. (L: 1592-1596).

Diagram 7.4 traces the role of global faith in Rachel's story alongside factors that assist coping.

Diagram 7.4



## **Tracey's Story.**

*Tracey is sixty years old. She is divorced, has two daughters and is a grandmother. Tracey was diagnosed in December 1994. Following the discovery a lumpectomy was performed on her breast. Since breast cancer, Tracey has given up smoking, alcohol and eating meat. She has also converted to Buddhism. Tracey is currently in remission, yet spoke about her breast cancer in a positive way.*

Through meditation, Tracey is able to establish inner confidence about things that trouble her; negative thoughts are replaced with positive affirmations and a feeling of well-being is embraced. Tracey began meditating when she was diagnosed in 1984. Since meditating Tracey reports that she no longer holds negative attitudes about life and her experiences with breast cancer. Further, meditation helps Tracey to manage panic attacks that began to surface after her diagnosis. (L: 2348). Tracey discusses the importance of meditation in the following paragraph,

When I meditate I find that place of peace of calm, of quiet. That sticker on my door 'I'm Shanti' means I am soul as well as a body. I was told that shanti means peaceful, calm, happy. There is a theory that our soul is peaceful, it is the peaceful part of us. We become distressed and scattered and fragmented, but our inner essence is calm. And when you meditate you can go to that part of your body that you feel is the core of you. And you know when you have found it because you smile for no apparent reason; you know it is from within you. It not reliant on looking at a pretty flower or smelling a nice smell or having eaten something nice, or somebody doing something nice for you. It is in you. It is inside you and you get to that spot and it is lovely. So you want more of it and you practice every day. Meditation makes you feel calm. It also allows the rest of the rubbish that you have accumulated to come up and only then can you deal with it. (L: 2349-2362)

Here Tracey discusses the importance of finding that inner core, that special place through meditation. Tracey trusts that her relaxation exercises will take her to a sacred place within, a place that will allow her to confront anger, pain and fear. 'It is only when you come face to face with the raw emotions of breast cancer', Tracey declares, 'that you can let them go, throw them in the wind so they can settle elsewhere' (L: 2363-2364). Tracey relies on her meditation to reach a state of inner peace. This reliance and commitment to practicing meditation on a daily basis allows her to exist in a state of harmony.

Tracey no longer suffers from depression, a condition she developed after her diagnosis,

I remember that during my depression I couldn't get out of bed. I would get out of bed to have something to eat, go to the toilet and I would run back to bed and pull the covers over me. I knew I shouldn't be doing it but I was doing it. I would get dressed and I would make myself go out for a walk. Then I would come home and do the same thing again. I just couldn't function in the way I knew I could, or should be. (L: 2397-2402)

Meditation has helped Tracey come to terms with her depression. Prior to Tracey's diagnosis of breast cancer she felt the need to control 'everybody' and 'everything'. Tracey was also very critical of the people she came into contact with, choosing to judge them on the way they behaved and thought. Certain events would cause her great anxiety such as family gatherings because she believed she was unable to control her surroundings (L: 2445-2448). Yet since breast cancer, Tracey reports that she is more accepting of the way things are and as a result feels less uptight and tense. These sentiments are expressed in the following statement,

Now I am much more accepting of the way things are. It makes me feel a whole lot better. I feel freer. I try to live for the moment, not even the hour, but the moment and that is meditation. If you can concentrate on just now, you're free and don't have any constrictions. So my meditation has helped me in that area too, to be accepting. (L: 2450-2454)

The support group that Tracey attends also provides her with the courage to tell her story. In being a member of a support group, Tracey is able to share deep concerns that cause her distress. The first ever support group that Tracey attended was called a foundation residential breast cancer school. It was at this school, whilst on retreat, that Tracey first began to realise that she was not alone in her suffering and that she was not the only woman to have ever suffered from breast cancer. There were twenty-four women present at this retreat who coped in various ways; some were dealing with breast cancer in an alternative holistic way while others chose more traditional modes of coping (L: 2285-2287).

Whilst at this retreat, Tracey was able to tell her story to the group. Tracey found the sharing of stories to be a healing process. Tracey speaks of the first time she told her story,

It was wonderful. I don't think anyone had ever asked me to tell my story before, there was never the opportunity. Seldom do people come up to you and ask how it has been. People might ask you how you are, but when you start telling them they really don't want to know. And I remember I was in the middle of the group from where Gen started and I thought there has been a lot of horror in my life and I can't remember much joy, even now. That's the way it is. And getting the gist of what other women were talking about I was thinking well I can say this and that, I won't bother telling them about that...I was compiling a story. I was making my story up for the audience, not for me. When it got to my turn I sort of went somewhere else. And I started off when I was a wee child probably three years old in my first memories and it just came out and it didn't matter. You know when they talk about being detached you know sort of looking at your life from another angle, another place, I was in that mode. In that stage I was able to talk about all those things that had upset me and how it was. And it was just so matter of fact. It had a powerful impact on the group. Everyone went into silence. Gen called a recession because my story was pretty awful...That was early afternoon and the next day I felt so light and I had this feeling of lightness in my chest, like a big rock had gone away. It was emotional, but I felt it physically. I was aware of the top of my chest and it just felt light. It is hard to explain. You feel light and I was floating around and I have been floating ever since. It was also suggested that we practice meditation to help facilitate our stress. (L: 2292-2337)

Tracey also spoke of the importance of going to church following her diagnosis of breast cancer. Church attendance taught Tracey about spirituality and visiting churches helped to calm Tracey when she felt anxious. Tracey's newfound spiritual connection is noted below,

I have come now to believe that God is the father, the supreme God and all these other religious leaders and founders all have their place, but the supreme is God. This belief makes me feel connected, secure. I like the feeling of belonging to someone. (L: 2464-2467)

Having a place where Tracey could visit during times of uncertainty enabled her to feel a sense of God in her life. Tracey now begins each day with, 'Good morning God, good morning world'. This encourages her to start her morning in an affirmative way,

I allow myself to be happy, to experience joy, to co-create an easy day, to co-create a fulfilling day. There is no panic, no anxiety. I have realised now that

this self-talk is important. You can say, "Oh I am not good enough, I am not worthy, I am too skinny I am too old, I can't". Sooner or later you will start believing these things. So positive talk is so important. (L: 2472-2477)

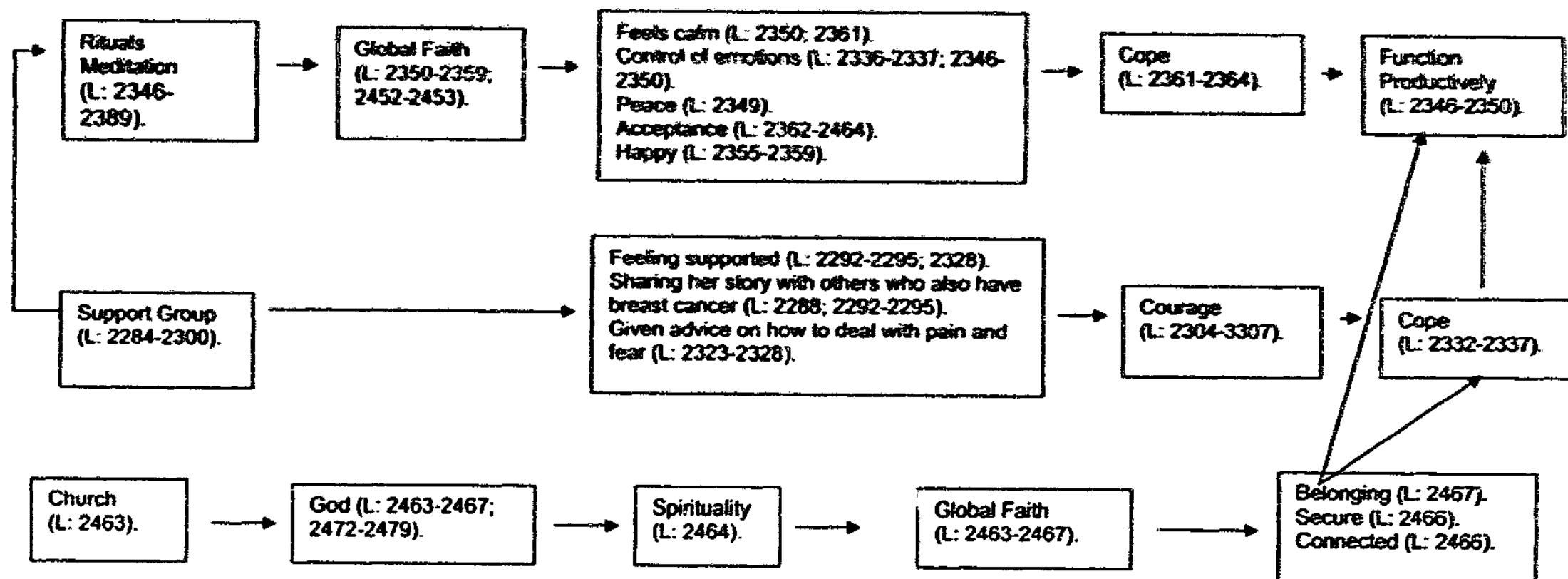
There are a number of factors that help Tracey to cope and global faith is one of them. Tracey's meditation allows her to move into a stage of global faith. The ritual of meditation empowers Tracey to view her world in a confident way. Tracey relies on her meditation to deal with dreaded thoughts and it is this reliance and confidence in the ritual she performs that leads her to global faith. Global faith is seen in her universal cosmic confidence in the world and the surrounding environment. Tracey no longer suffers from depression and anxiety attacks. Since meditating her world is no longer something that needs to be controlled and manipulated. Meditating has allowed Tracey to accept certain aspects in her life. In being able to accept her surroundings Tracey is able to cope and function in a productive way.

Global faith cannot be linked to Tracey's support network. Attending these meetings helps Tracey to deal with uncertainties pertaining to breast cancer in a direct way. In sharing her story with other women who also have breast cancer, Tracey comes to realise that there are individuals who experience similar fears. Courage to face the day evolves from her interaction with other women. Having courage assists Tracey to cope with breast cancer; courage provides her with the necessary strength to begin her day in a confident way.

Tracey's church attendance also plays an important role in her recovery. When at church Tracey feels close to God. Her belief in God leads her to a level of global faith. She states, 'Going to church makes me feel connected, secure. I like the feeling of belonging to someone' (L: 2466-2467). Feeling connected to a spiritual force helps Tracey to cope. Each morning Tracey greets God and believes that such

a greeting allows her to begin her day in a cheerful way. In being able to trust in a higher force, Tracey is able to view her surroundings with self-assurance. In perceiving her world in an optimistic light, Tracey displays global faith. Tracey is no longer frightened to get out of bed and now seizes the opportunities that each day brings. Diagram 7.5 examines coping mechanisms in Tracey's story

Diagram 7.5



## **Rosa's Story.**

*Rosa was diagnosed with breast cancer in June 1998. Following her diagnosis, she had a mastectomy and a breast reconstruction at the same time. In April 1999 Rosa had her first reoccurrence and underwent a second operation. She is currently in remission, yet suffers from hot flushes as a result of her treatment. Rosa is thirty-five and is married with two young children.*

When diagnosed with breast cancer Rosa expressed her appreciation at having her mother's friends and work colleagues pray for her health. This ritual inspired Rosa to get better. Rosa reflects on this time,

I would hear that the staff would have seminars and they would pray for me and I would feel very moved by that stuff. And you know I wanted that. My mother goes to church all the time and she has this prayer group on a Tuesday night. And her girlfriends would come around and put their hands on me for a healing session and they would generate so much energy. And that was my little initiation. And I would feel so much lighter until I got to the point where I would say to my mum, "Why don't you bring your friends?" Her friends did the whole thing with the hands and healing and it restored my faith; they were so loving. I have to believe because in the whole time I have experienced this I have met people that have been absolute angels and I feel so privileged. (L: 1492-1501)

Before Rosa had breast cancer she was cynical about God and religion. Even though she was raised a Catholic, went to a Catholic school and eventually ended up teaching at a Catholic college, she was not interested in religion. She explains, 'Right from the beginning of my appointment I actually said to my principal, "Don't even think about ever giving me religious education classes. I am not interested". I never felt like I knew how to handle religion. I was such a cynic. I had too many questions about God and whether he existed' (L: 1366-1369). Yet, this cynicism did eventually change once she was faced with a life threatening disease. When Rosa's was diagnosed with breast cancer she found a need to cling to her religion and seek from it peace from suffering. We see this in her following statement,

The feeling of aloneness that takes place when you are told that you have cancer is so horrible. The only way out of the darkness is to feel some kind of hope and I have to trust that there is something more than physical stuff. You are trying to make sense of what's happening to you. I look at some of the things that happened in my life and I believe at some point there have been

too many things that have happened that may have been um like the opportunity to go down a more spiritual path. Those paths were there but I resisted them. And then I ended up with breast cancer and things changed. I still feel a bit embarrassed. I would love to go to church on a Sunday because now when people speak in a spiritual way you're always very keen and you listen harder. (L: 1377-1388)

Rosa views meditation as important in her ability to cope with breast cancer. Rosa meditated twice a week while recovering from breast cancer and this helped her to remain focused. Meditation also allowed Rosa to find tranquillity within and this encouraged her to face her day with strength and vitality. Rosa speaks of meditation in the following way,

During this time I was meditating twice a day and I felt completely focused. I feel like I am not doing this alone, there has to be some higher being here. Through meditating I feel I have become a bit more spiritual. I stopped the meditation at the end of Jan when I found a lump in my scar and that was when I hit rock bottom. I started feeling that terror again and it's not rational stuff and that's what you feel. That's when I joined the group. But I know that talking isn't enough. I have to get back into meditation so I have been trying to do meditation at least twenty minutes once a day and I feel much better. I am quite busy at the moment. I am struggling to find time for it, but I will. I am absolutely determined so I will pick it up again and be consistent with it (L: 1352-1361). When I meditate I will get up before the kids and I feel like I am ready to conquer the world. (L: 1433-1434)

Having two young children is also a key factor that empowers Rosa to fight her illness. There were times when Rosa would sleep in the same bed as her son and this had a calming effect on her state of being. Everyday spent with her children is priceless. The thought of someone else watching her children grow and nurturing her children's needs empowers her to maintain a fighting spirit.

I just don't want to imagine anyone mothering my children except me. That's why I have to be positive and believe that I am going to be all right. I am going to get through it because I have every reason to believe that and the kids are the main reason and my main reason for fighting (L: 1476-1480). Everyday I treasure being with my kids. I try to enjoy everyday with my children...everyday is absolutely sacred. The thing that causes me the greatest grief is the whole prospect of not being here for them when they grow up. I pray madly that I am here for them. My kids are absolutely besotted by me; they love me like only a mother can really know. So that's what makes me cry in the end, the whole thing about death. Death used to scare me a lot and it still does, the whole prospect of dying, but what scares me the most is imagining their life without me and that's why I had to do the stuff like meditation. I have every reason to get better. I have to because I have these kids who I just adore. When I get really upset I think about my children. All you

really want as a mother is to protect your children from things, from really unhappy sad scenarios. I want to protect them from their mother dying of breast cancer. When you end up with breast cancer your whole world just sort of collapses and you will do anything to bring it back to some kind of normality. My kids are my main source of strength. I have them in my life and I have to make the most of it. (L: 1455-1471)

Rosa views her support group as being valuable in coming to terms with her emotions and fears. She enjoys the outings with her support group and the opportunity to discuss their stories in a setting that is not clinical or medical. She explains,

I cope by looking at women like me. I go out for dinner once every six weeks with the group and we sit around and we laugh. We are in a restaurant; we are not in a hospital, or a cold clinical horrible place that constantly says you are sick you are dying. It is so therapeutic being surrounded by women who are laughing, who are just getting on with stuff, doing really meaningful stuff, doing ordinary stuff. (L: 1345-1349)

There are a number of factors that help Rosa to cope. In seeking the healing hands of her mother's friends during her illness, Rosa believes that her faith has been restored. In believing that these women were a gateway to a transcendental force, she sees herself as spiritually nourished. Her trust in a higher being is evidence of global faith. In being confident in the magical powers of her mother's friends, Rosa feels supported and loved. Such outcomes to her global faith are an ability to face the day ahead and she feels safe from harm and danger.

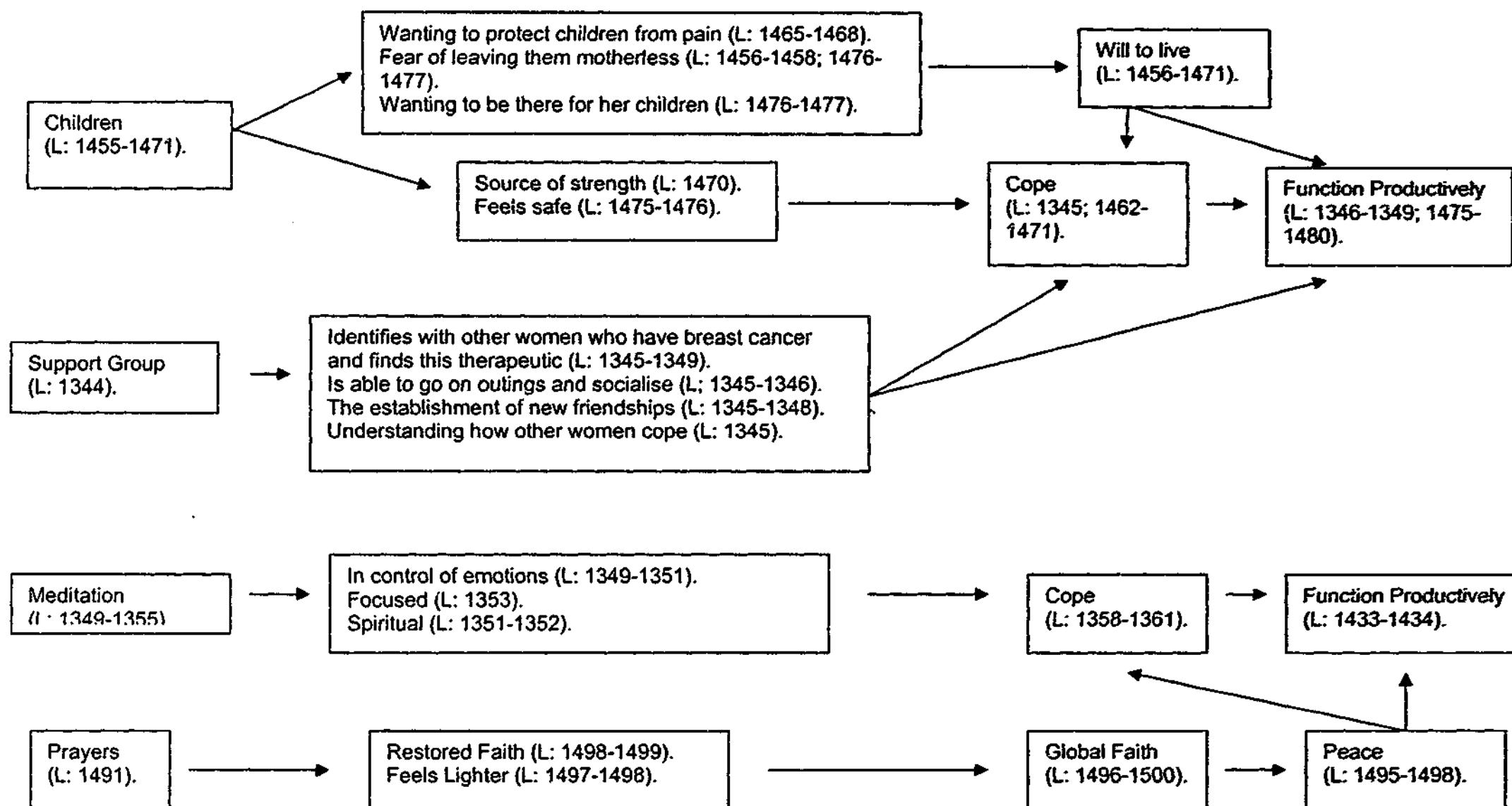
Rosa's children are the source of her will to live, but do not lead her to global faith. In wanting to mother her children and in fearing the pain she may inflict upon them if she were to die, Rosa remains positive about her recovery. Adopting a fighting spirit helps her to face the day ahead. Meditation also allows her to focus her emotions so that she is able to be there for her children.

Meditation is linked to spirituality, but not to global faith. When Rosa does not meditate she experiences the terror often associated with a diagnosis of breast cancer. In being able to meditate in the morning, Rosa adopts the attitude that she is able to 'conquer the world'. It is this attitude that allows her to maintain a core optimism of the day ahead.

Rosa's support group helps her to come to terms with her illness. Here she is able to identify with other women who have similar problems. In being able to widen her network of friends, Rosa also enjoys the social activities linked to this group. Discussing treatment and problems in a restaurant, or a café, helps Rosa to feel that cancer does not always have to be treated in a clinical way; cancer is normalised when women are able to display characteristics of moving on and enjoying their lives.

Diagram 7.6 traces coping facilitators in Rosa's story.

Diagram 7.6



## Keely's Story.

*Keely was thirty-four when she was told she had breast cancer. After being diagnosed in 1995, she had a partial mastectomy of her right breast. Keely is thirty-eight years old and is married. She has two children from a previous marriage. Keely also prefers to use the word 'cured'. She has been 'cured' for four years.*

Prior to breast cancer, Keely was not a gardener; in fact she found it boring and chose to do other activities to fill her time. Yet, things began to change after her diagnosis. Keely took up gardening and found this hobby a source of great relaxation and comfort. She tells me that when she was diagnosed with breast cancer she needed something to do, some kind of outlet through which she could take her mind off her illness. It was gardening that provided her with what she calls her 'sanctuary'; gardening gave her the serenity she desired after a hard day's work and allowed her to feel a sense of calmness within. When weeding, or tending to her flowers, Keely is happy and enjoys the sacredness of her special place,

My garden is my sanctuary. I feel close to people that I have lost like my Godmother, my grandmother and my grandfather who were all great lovers of the garden and it is almost like you have your own little spirit world happening out there and you've got something spiritual. Some people go to church and light a candle, for me I go out in the garden. (L: 3498-3502)

Keely's garden is also a tool that helps her to connect and make sense of the various stages of her illness. Keely buys sick plants that are dying; she brings them into her garden that is her sanctuary and resurrects them. Keely tells me,

Yeah one of the things I have done in my garden is I go to nurseries and I buy all these plants that are sick. I bring them home and I trim them back and give them a good feed and a bit of TLC and I get such a thrill when it grows. I always have a conscious thought go through my mind that this plant started off like me. Like me it is broken, patched up and is now as good as new. (L: 3494-3498)

Keely's breast was cut off, her cancer was removed and she was physically ill as a result of chemotherapy. Gradually she was able to overcome her fatigue, nausea and slowly regain her strength. The sick plants are metaphors of her battle with

breast cancer. When these sickly plants rise above the odds of their survival and blossom into beautiful plants, Keely is happy.

Once Keely stopped her treatment for breast cancer she made a lot of life changing decisions. She tells me that not long after her treatment she decided to leave her job. Keely had been unhappy at work for some time, yet had never thought of leaving until faced with cancer. Breast cancer made Keely realise that life is too short and that she must treasure the time she has left. Once Keely resigned, she and her husband decided to take an overseas trip,

At the same time my husband had just resigned and taken out his long service leave so we went out and bought two tickets to Greece and we went overseas for a holiday. Just like that and that is something I never would have done. I was always a planner and you have to think things through and always have a contingency plan for stuff and I am not like that any more. Now I tend to feel if I am going to do something I'm just going to go out and do it. I am going to enjoy what I am doing, enjoy my life, enjoy my kids. So breast cancer has really turned my life around in that way. I enjoy my life a lot more now. I have a different outlook. There are more important things to worry about than whether your mortgage is paid off. It's not important. When we bought this house we had quite a large mortgage. We could have paid off a lot more of it, but we chose not to. We chose to keep the cash and we bought a new car and had a holiday. I figure whether I pay my house off in twenty years or thirty years, it doesn't really matter. And if worst come to worst and I lose my house and I have to live in a caravan, big deal. I still have my husband and I've got my kids. (L: 3374-3388)

Keely also had an experience in hospital that gave her the feeling she was being looked after by a higher power. It was this that made Keely feel that a divine force was watching over her. Here is Keely's account of what occurred one night whilst in hospital,

I had an experience when I was hospital that made me believe that I was being looked after, whether it be God, or a guardian angel or whatever, it gave me a real sense of security, a sense of someone looking out for me. I was actually asleep in the hospital bed and it was about three days after my surgery. It was in the middle of the night and I woke to this sensation of a cool hand on my forehead and I thought it's the bloody nurse again checking my blood pressure because they are always coming to check up on me. And I felt this coolness on my forehead and I opened my eyes and looked to where I expected the person to be and there was no-one there and I turned my head to the other side and there was no-one there, but I could sort of get the image of light. And just for a split second I saw an image of my uncle who had

passed away many many years earlier. And I saw his face and we were really close and I saw his face and he looked really well and happy and it was just this golden, orangy light and he just looked at me for a split second with a smile on his face and he was gone. And I thought Ted is looking after me. I had never had anything like that before. And then the next thing that went through my mind was shit if he is dead and I can see him then I must be dead too. And all these thoughts are going through my mind and I thought no I am awake and I buzzed like crazy and the nurse came and I didn't tell her anything that happened because they would stick me in a psych ward or something. I called the nurse and realised that I was fine. It was funny I used to think about that constantly, I still do. It gives me a feeling, it's not just God, which is sort of an abstract thing. To me it is more personal. It's like I've got someone there keeping an eye on me. (L: 3549-3570)

There are a number of factors that facilitate Keely's ability to cope with breast cancer. Keely's garden is one such factor; her garden is a place where she can unwind from her day. Stress and worries are soon forgotten when she is in the garden,

I can come home and have a really bad day at work and I will go straight out in the garden. And I'll just go out there. Even if I just walk around or pull out a few weeds, or trim the roses, or whatever and come back in and before I know it, like an hour or an hour and a half has gone and I will come back just so calm and relaxed and it is wonderful. (L: 3451-3455)

Keely refers to her garden as her 'sanctuary' in that she is able to forget about her problems and 'feel at peace'. Keely discusses her connection with close relatives who have passed away. It is in her garden, her 'spirit world', where she is able to connect with her godmother and grandparents. In feeling a connection with her dead relatives, she 'feels close to people', who have died. There is little evidence of global faith here. Her garden is a source of enjoyment that offers her serenity.

The sick plants that Keely revives are also symbolic of her own journey with cancer. These plants are a source of great encouragement and hope and provide her with a tremendous amount of satisfaction when they overcome their odds of survival. Whilst there is no evidence here of global faith, Keely's sick plants sustain her fight to go on despite the threat of uncertainty.

Leaving work helped Keely to ease the burden of being in an unpleasant working environment. In going overseas with her husband and in taking the time out for herself, Keely is satisfied that she made the right decision to 'loss' her job. Further as she explains, 'I am going to enjoy what I am doing, enjoy my life, enjoy my kids. So breast cancer has really turned my life around in that way' (L: 3378-3381).

Having cancer changed Keely's outlook to life. Keely did eventually find a new employer and had this to say,

My new job really helped. I always think that anyone that has cancer should do some time of work, whether it be part time, or job share. Otherwise the only thing that you have in your life is cancer and treatment. Whilst I was having treatment I worked for a few days and that helped. (L: 3429-3432)

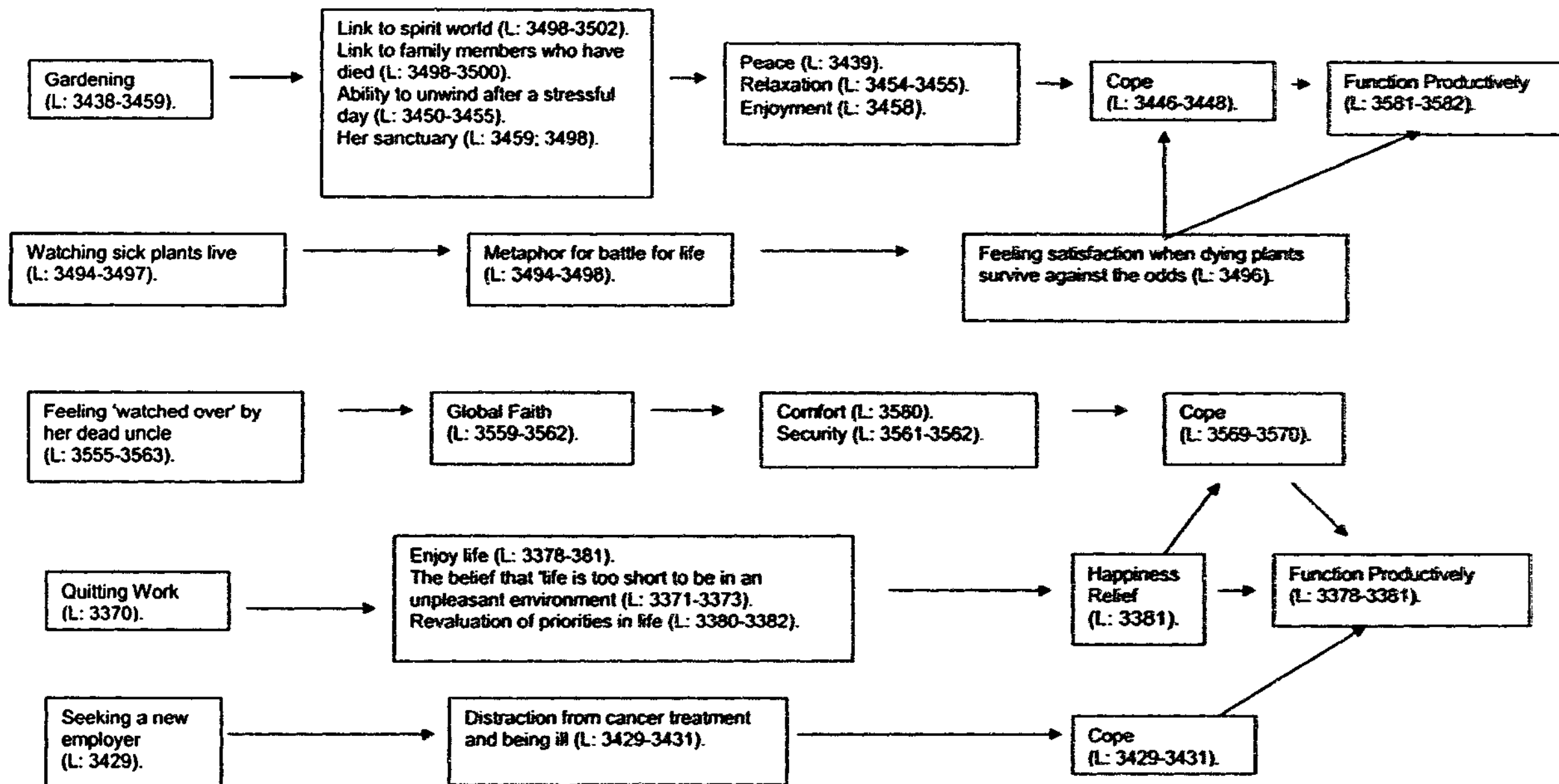
In being able to focus on other things in life, besides her cancer treatment, Keely was able to deal with her illness in a better way. Work helped to establish a feeling of normality in Keely's life. This assisted in her ability to cope with cancer.

The only evidence of global faith in this narrative is Keely's discussion of her dead uncle. Here we see a belief in a higher being that facilitates a feeling of trust in her external environment. When Keely speaks of her dead uncle she distinctly says,

And I saw his face and we were really close and I saw his face and he looked really well and happy and it was just this golden, orangy light and he just looked at me for a split second with a smile on his face and he was gone. And I thought Ted is looking after me. I had never had anything like that before. (L: 3559-3563)

In relying upon her dead uncle, Keely believes she is being watched over and looked after. Such a feeling links Keely to a level of global faith in the world and her surrounding environment. Outcomes to this confidence are that she feels a sense of security and this helps her to function in a productive way. Diagram 7.7 traces the various sources in Keely's life that facilitate an ability to cope with breast cancer.

Diagram 7.7



## **Kerry's Story.**

*In 1996 Kerr was diagnosed with breast cancer. She was thirty-four at the time. Kerry had a mastectomy and endured radiotherapy treatment. Kerry has since had a breast reconstruction and she is happy. Kerry is single and lives on her own. Her family live in the country and she lives in the city. Kerry does not use the word remission and prefers to see her cancer as something that has gone away.*

Inspirational people in Kerry's life were important to her during her time with breast cancer. Kerry spoke of this,

I think I am a spiritual person. I had a bit of an interest in spirituality before cancer. I do love people who are so inspirational. I am in the Australian women's pilot association and they are the most incredible people you can meet. A friend of mind is in a wheel chair and she flies. The things she has had to endeavour in her life have been incredible. And everyone influences every one in different ways. I really like to read inspirational books and I love being around people who are amazing in what they have done and what they believe they can achieve. (L: 316-322)

Having someone to admire and look up to helped Kerry to feel encouraged during her recovery from breast cancer.

Kerry also outlined work as being important in her recovery. With work came a need to look presentable at the start of each day and this helped Kerry to cope. She explains,

One of the big things when I had cancer was that I made sure I looked nice each day. I made sure that my hair was nice. I do that anyway but this time I knew that if I looked all right then I would feel all right. If I got up and looked in the mirror and saw I was in an exhausted state it would frighten me. So that was a big thing for me. Looking nice and fresh and happy and that was how I wanted to commence each day. (L: 287-288)

Yet, Kerry eventually had to take time off work during her treatment. Whilst undergoing radiotherapy the strain of working became too much (L: 244-246). It was during her time off work that Kerry regained her strength and dealt with issues that troubled her. This is noted in the following passage.

When I was off work I thought I have to change my life in some ways. I think I decided that I needed to feel peaceful so I really worked on that. There were

family issues that I realised had completely stressed me out and I worked through all of that. I confronted them and dealt with them. I am more selfish with myself. I had previously put everyone else before me. I don't do that now. Another thing that has changed is my attitude to work. If I am feeling tired at work, I will take a day off. I wish I did that before. It is so important. Having cancer has made me think about my own needs and I am responsible for looking after my well-being. (L: 273-281)

In being able to take time out for herself, Kerry concerns herself with her own needs which aids in her recovery.

Support groups played a pivotal role in empowering Kerry to come to terms with emotions attached to having breast cancer. Kerry, a founder of a support group for young women, spoke of the importance of interacting with women who could truly understand the array of emotions she faced,

I think it is good to be around people who are your age. They really know what you have been through and these young women know what you are thinking and where you are coming from. Even if you go along and you don't even talk about what has happened to you, you know that there is that understanding there. Because no-one else wants to know about your worries (L: 254-358). When I was firstly diagnosed, I kept on going to groups where there were older women. I kept saying to them, "Your needs are so different to mine". These women didn't feel this was true. One night I said goodbye to all of them. As I was walking out the door I thought to myself most of those women are going home to their families, their children, their husbands. I don't have that. I am going home to a house on my own. I thought that was interesting. (L: 337-342)

The need to speak to young women who were experiencing similar emotional and physical problems as a result of breast cancer and treatment is important to Kerry. The support group she attends now provides her with a variety of sources to draw upon. Being able to connect with younger women has also enabled Kerry to cope.

Whilst there are a number of sources that facilitated coping there is little evidence of global faith in Kerry's story. During her battle with breast cancer, her work for some time provided her with a distraction. In having to get up in the morning and look nice, she felt, 'fresh and happy'. Yet, when Kerry had to leave work because of her state of exhaustion, she also saw this as a time where she could think about her own

needs. In adopting the attitude 'I am accountable for myself', she is able to take control of her recovery; Kerry feels confident that only she is able to make herself better. In having time off work, Kerry had a breast reconstruction and this makes her 'happy'. Addressing her own personal needs has helped her to adjust to changes in her life.

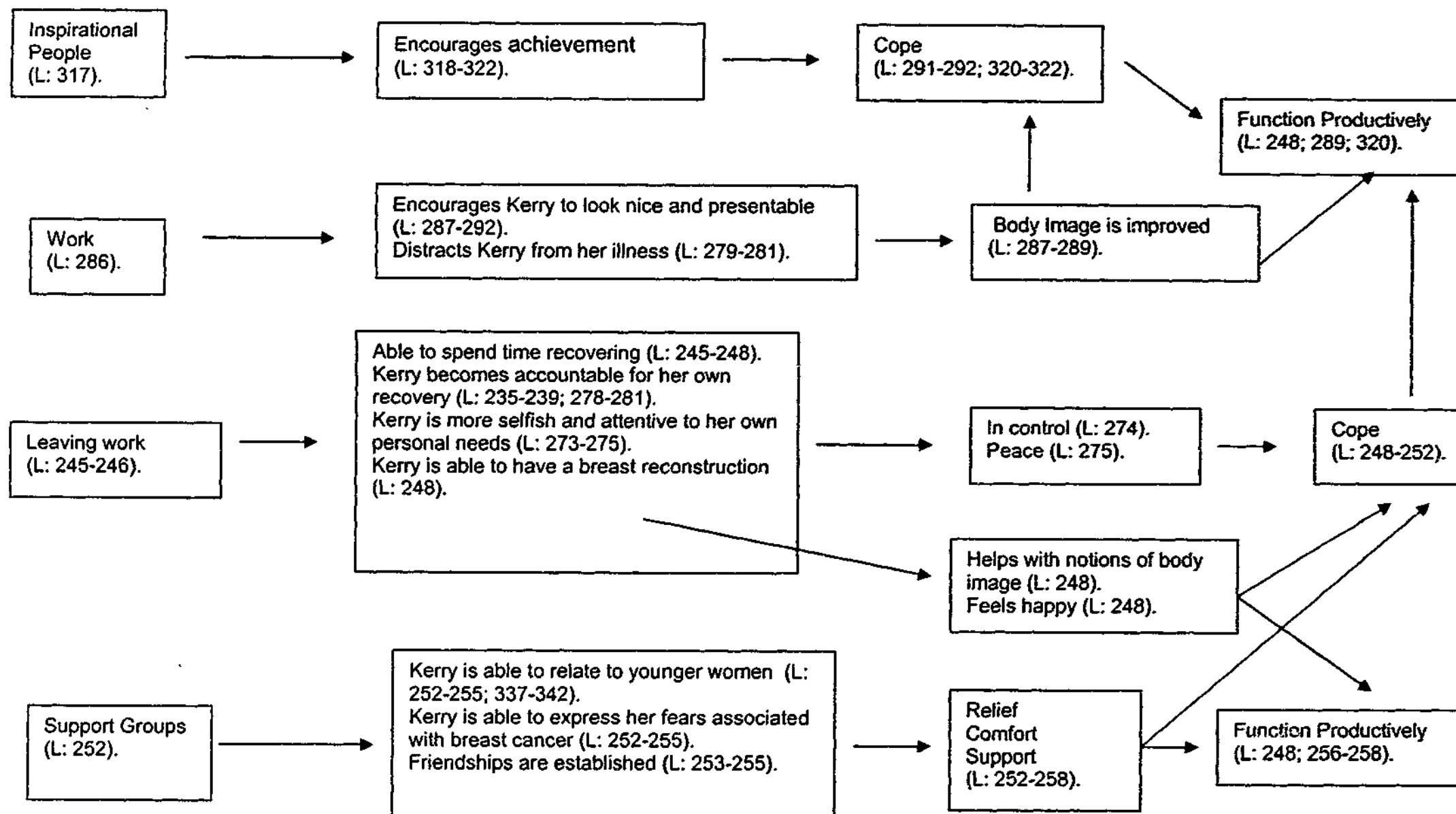
The support group that Kerry attends is important because it allows her to interact with women her own age who have similar problems. Here she is able to discuss problems associated with breast cancer and also establish friendships in the process. There is no global faith present here. The support group facilitates a feeling of connection and bonding which assists with her ability to cope and view her life in a positive way.

Inspirational people are important in Kerry's life, as it is their strength and determination that gives her the courage to face her own illness. We see the impact of inspirational people in her life when she states,

Everyone influences every one in different ways. I really like to read inspirational books and I love being around people who are amazing in what they have done and what they believe they can achieve. (L: 320-322)

In being a member of the Australian women's pilot association (L: 317-318), Kerry is made aware of how other individuals battle tragedy. Kerry's friend, who is wheelchair bound and flies, makes her aware of the importance of setting goals and seeing them through. Kerry is also aware that others influence her outlook to life (L: 318-320). We see a direct influence upon Kerry by those people she comes into contact with. Coping with her illness is assisted by her interaction with other individuals who deal with their problems in a challenging and functional way. Diagram 7.8 traces the various sources that assist Kerry to cope with breast cancer.

Diagram 7.8



### **Sarah's Story.**

*Sarah is fifty-four and was diagnosed with breast cancer when she was forty. Following her diagnosis she had five weeks of radiotherapy, a lumpectomy and eventually a mastectomy. Since her first diagnosis there have been two reoccurrences. Sarah did have a breast reconstruction yet unfortunately there were complications. These complications led to her being hospitalised four times in one year. Sarah has been married for twenty-nine years, yet lives in a separate part of the house from her husband. Sarah has three children who have been a source of inspiration in her life.*

Sarah's story draws attention to life changes. Her decision to sleep no longer with her husband after being married for twenty years is a direct result of being faced with a life threatening disease. Since her diagnosis Sarah has made a decision to live a separate life from her husband; they now sleep in separate rooms and live in separate parts of the house. Sarah's determination not to share her life with her husband after twenty years of marriage has meant adopting a different lifestyle — she regularly goes out with her friends on her own and is fairly independent in her chosen activities. Whilst Sarah believes her problems in her marriage have not been solved, she sees the changes in her life as being 'revolutionary' and 'big'. Sarah now has her *own* life outside of her family and has established her *own* circle of friends. In choosing to act and think in a way that will benefit her emotional and physical state of being, Sarah is happy. She explains,

When I got cancer straight away for the first time I started questioning my marriage and things have now changed in that relationship. Now there are certain things that I am not prepared to accept within the relationship. Before cancer I didn't ever question the problems I had in my marriage. I played dumb, closed my eyes and my ears to things in the relationship. But the moment I felt I really didn't have that long to live, or maybe there was a threat to my life, I changed in my thoughts. But of course I have spoken to other women whose changes have been more radical than mine. I don't have the courage to make complete changes. So the decision I made was quite a big one, but not as big as I would like and that's because of hurting other people. I am a businesswoman so I couldn't just pack up and leave. It would hurt too many people (L: 396-405)... I should have made more decisions, but I did make some revolutionary ones. And one of the main ones was that I tried to be more selfish because I don't think women are selfish enough. I have my own life outside of the family now. I have a great bunch of girlfriends who I rely on a lot. Friendship was something I never gave much time to before cancer (L: 410-415)...Going back to where I changed I have to say that I am still in a marriage where there is no emotion or passion and always hid it. I still live with this

wonderful man. I mean he is good and kind and a wonderful father and all those sort of things, but there was virtually no sex in the marriage. That was cool because there was so much more benefit in the marriage and he was a good man. Prior to breast cancer I would think to myself oh this is fine. So for twenty years of marriage I never said anything about it except to him and he couldn't change. So in fact three years ago I threw him out of the bedroom because I wanted my own space. That was definitely because of the cancer. He now sleeps upstairs and I sleep downstairs. I must make my own life now. I try to include him wherever possible, but generally speaking I make my own life now. (L: 436-446)

Sarah believes that since her diagnosis with breast cancer she has become more selfish with her time. When she was first diagnosed she took on a trainer who helped her with dietary, vitamin and fitness issues. She also began running and working out at the gym, taking charge of her health and her physical state. Sarah explains,

You know I wouldn't have had a trainer if I hadn't have had cancer. Somehow I wouldn't have been selfish enough. I consider having a personal trainer selfish and self-indulgent and now I can justify doing things for myself. (L: 490-593)

Sarah sometimes partakes in yoga exercises and believes this ritual links her to a spiritual dimension. She enjoys fasting and adopting an alternative style of existing believing this to be a key factor in precipitating a feeling of 'cleanliness within'. She exclaims,

I do love this path of fasting and this different alternative style of living. It makes you feel clean. This feeling comes from the yoga so I suppose it is sort of spiritual, yeah it is spiritual because I love it. (L: 507-509)

Many women have spoken about the ways in which breast cancer has made them more attentive to their own personal needs. Some women like Sarah even go so far as to say that they are more selfish as a result of breast cancer and no longer seek to please others. Instead their main concern is what they really want out of life and what is ultimately going to make them happier people. It is interesting to note that most of the women interviewed adopted this 'selfish stance'. Whether it was reassessing friendships or spending more time at cafes, or at the beauty parlour, their outlook on life changed. With the onset of cancer, what these women once tolerated was

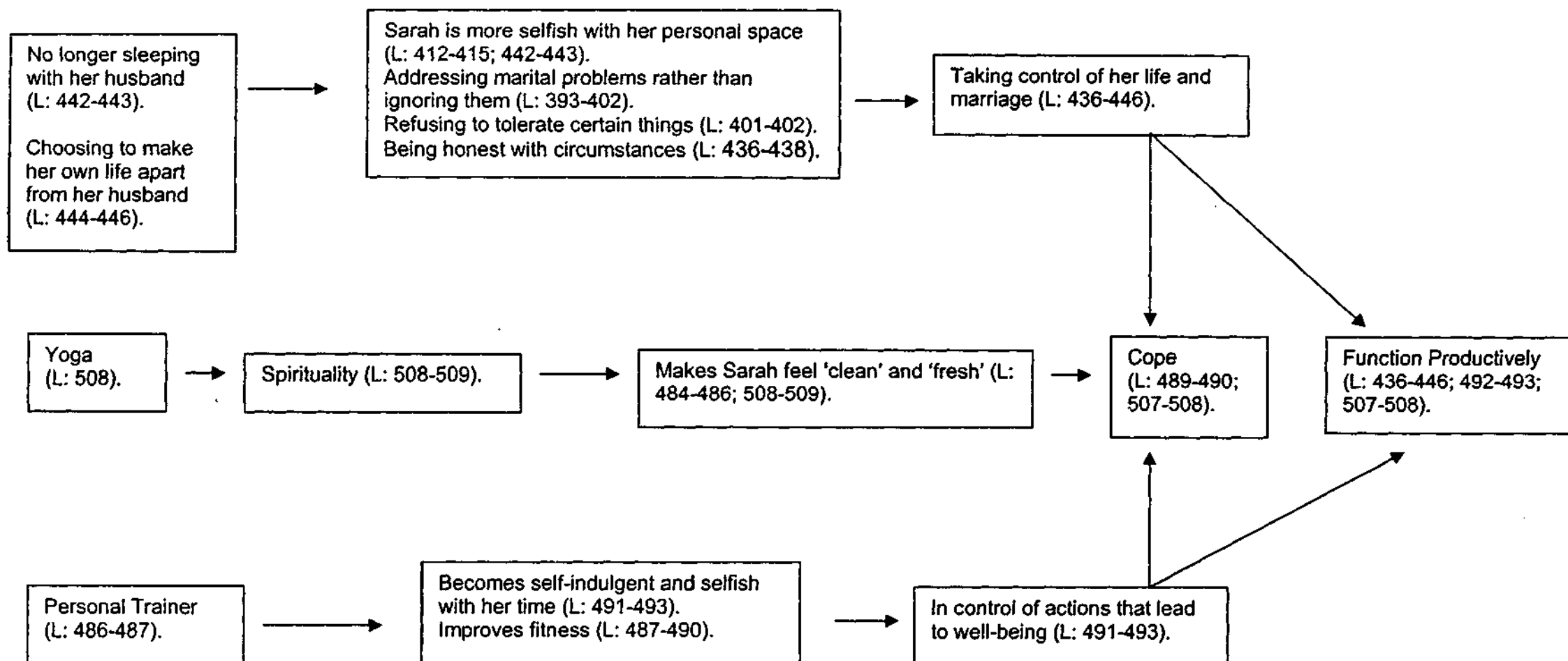
tolerated no more. The determination of these women to transform their lives meant that revolutionary decisions were often made and their lives would never be the same.

There is little evidence of global faith in Sarah's story, yet we can see a number of factors that help her to cope. Adopting a more selfish attitude to her own space and choosing how she wishes to spend her time are seen to generate a sense of control in her recovery. Sarah comments on her self-indulgence, an indulgence that she believes has resulted from a diagnosis of breast cancer. In hiring a trainer to help her with her fitness, Sarah believes that she is contributing to a strong fitness level. Being fit and healthy helps her to remain positive which assists coping.

Sarah's decision to separate herself from problems faced in her marriage do not take her to a level of global faith. In choosing to no longer sleep in the same room as her husband there is an element of control being taken in her life. It is this control that allows her to view her marriage in a different way. We see this when she states, 'I must make my own life now. I try to include him wherever possible, but generally speaking I make my own life now' (L: 444-446). Coping for Sarah has meant making decisions in her marriage that allow her to feel removed from a strained sexual relationship with her husband; in leading a separate life to that of her husband Sarah feels she is being responsible for her own happiness.

Finally Sarah is seen to attain a level of spirituality from her yoga. In practising yoga she achieves what she terms as a 'clean feeling'. She enjoys this feeling and likes to begin her day in a certain frame of mind. Yoga therefore facilitates a level of psychological control and is seen by her as a spiritual. Having this attitude to her body helps Sarah to view her recovery in an optimistic way. Diagram 7.9 traces the factors that facilitate coping in Sarah's story.

Diagram 7.9



### **Rebecca's story.**

*In 1983 Rebecca was diagnosed with a benign tumour in her left breast. She was thirty-seven at the time. On the same day she was told that she was eight weeks pregnant. Had the tumour been malignant Rebecca would have had to abort the foetus. Following her diagnosis she had a mammogram every year. It was during her ninth mammogram in 1997 that a lump was discovered in her right breast. This lump proved to be malignant and she underwent a partial mastectomy and an axillary clearance. Rebecca also had radiotherapy for thirty-three days. Rebecca went into remission for two and a half years. It was during her interview that she told me that her cancer had returned. It was now in her seventh rib. Rebecca has been happily married for twenty-four years and has a teenage son. She regularly attends a support group once a week.*

Rebecca suffered a nervous breakdown following her partial mastectomy. A year after her operation She experienced intense pain in her back and groin which contributed to her state of depression. Another factor that added to Rebecca's state of depression was being forced to leave work. While recovering from chemotherapy, she missed interacting with her work colleagues and this added to her isolation and alienation. Rebecca tells me of this period in her life,

I had a little job that I really enjoyed. I am a recorder for weight watchers and when I couldn't do that any more I got really depressed. I think that led to the breakdown too because I was home all the time and I really wasn't well enough to go out or work (L: 549-552). I just got so frightened to go out. I started crying and I don't know really why. I was worrying about all silly things, financial things. Being here on my own and not being well meant everything got on top of me. I had no support groups; I had no one to talk to. Maybe if I had of gone to the support groups from the start I would have been all right (L: 610-614). There was one friend who had been through a breakdown and she was on nerve tablets and I spoke to her and she was a big help. And I knew that I needed help, it wasn't me. I think at one stage I thought, "I wish I was dead". (L: 624-626)

Attending a support group empowered Rebecca to deal with her illness. Being able to discuss her fears helped her to come to terms with her illness. We see this when Rebecca reflects on her first support group meeting,

When I first went to the meeting I was scared. I thought I was going to cry you know. I didn't know the people and I didn't want to cry. And they were so nice that I thought I wish I had of gone their sooner and I wish I had. I think that all women, who have had breast cancer, if they can handle it, should get counselling. They should be spoken to in the hospital because I wasn't. My counselling came through the support group and then I got on top of it too. I did

some research and stuff and started reading up on books and that helped. (L: 640-646)

Rebecca also spoke of a number of other things that helped her to cope with breast cancer. These included going out with her friend Jill and having the support of her son's homeroom teacher at school. Rebecca was also comforted to know that her son's R.E teacher was there for her son if he needed someone to talk to,

My son was also very good as well. His teachers were good too. His homeroom teacher rang up to see how I was. Now the cancer has returned in my ribs and I rang her to keep an eye on him. She said she would. And his R.E teacher Miss Ryan was very good. This helped me so much because I knew that he would be watched over. (L: 558-562)

Rebecca spoke of a belief in God, having a sense of God in her life and becoming more religious as a result of having breast cancer,

I believe in God and give thanks to my life and I realise how lucky I am. Although I am not rich, I am rich in other things. I have good friends and family. I became a little more religious once I was diagnosed, but I don't go to church every Sunday. I do have a sense of God. I am not scared of dying. I know that might sound morbid. (L: 680-683)

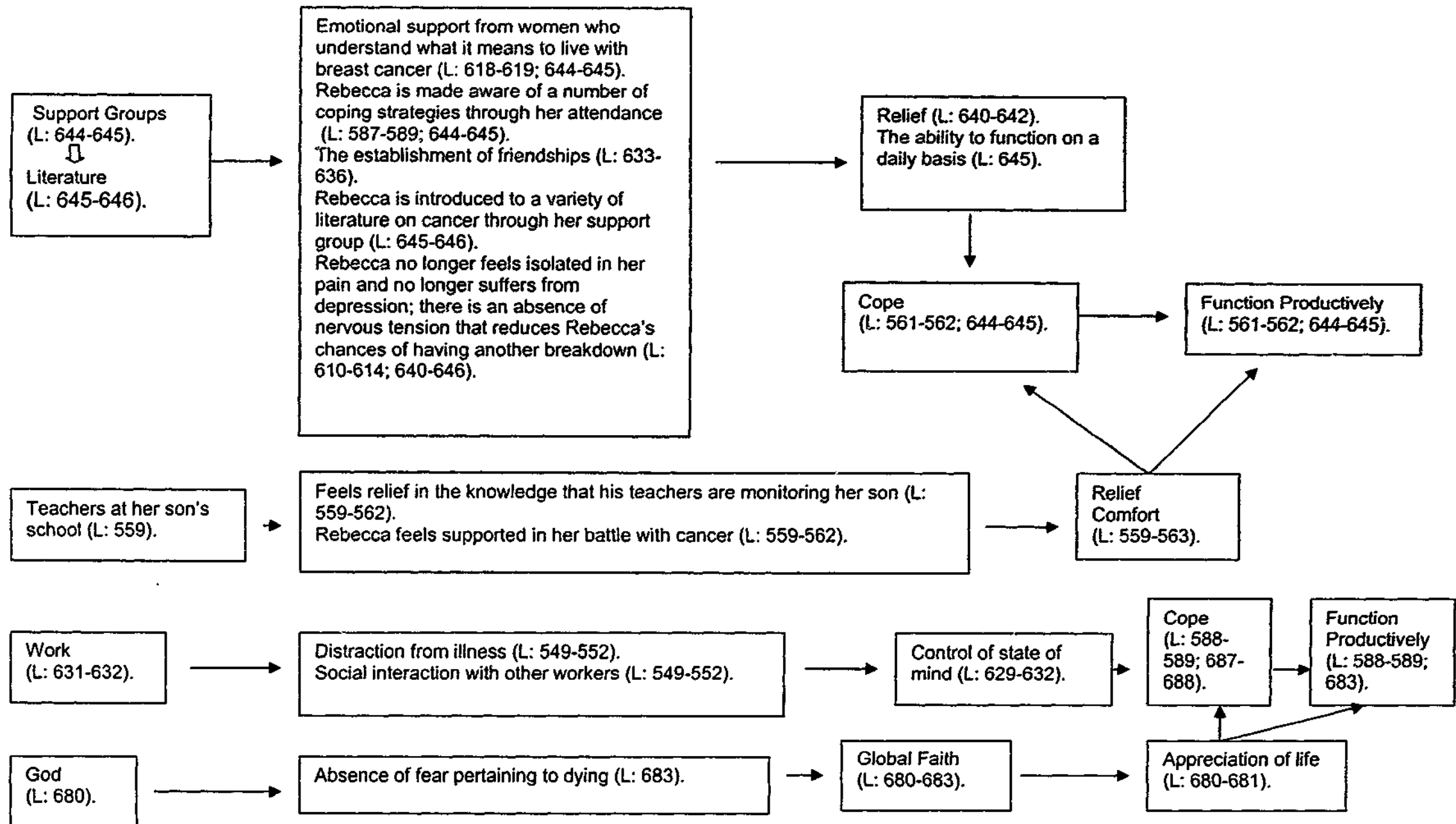
There is no evidence of global faith here. Yet, there are a number of factors that facilitate Rebecca's ability to cope with cancer. Her support group is important in her recovery. It is through this support group that she is able to openly discuss her fears related to cancer. In being able to tell her story and in listening to the stories of others, Rebecca is comforted in the knowledge that she is not alone. Prior to attending this group Rebecca suffered from a nervous breakdown and lost the will to live. She wanted to die and did not feel in control of her emotions. Such negativity is no longer present in Rebecca's life. Whilst her cancer has returned in her seventh rib, Rebecca is still hopeful that she will recover. In being able to view her illness in a positive way Rebecca is able to overcome certain fears and can function in a productive way.

Work is important in Rebecca's life. In working for weight watchers, she is able to interact with co-workers. In being around other people, she no longer feels alone and isolated. Being able to involve herself in work also helps to distract her from her illness; this distraction helps Rebecca to cope. Work is not tied to global faith. Rebecca's work directly assists her ability to function at a positive level.

Rebecca feels fortunate that her son's teachers are looking after him. This provides her with a sense of relief. In feeling supported by her son's school, Rebecca feels reassured that her son is being cared for. Teachers and the school facilitate a feeling of security, which helps her to cope.

Finally a belief in God helps Rebecca not to fear dying. It is her sense of God in her life that gives her the strength to embrace death and the dying process (L: 682-683). Here we see evidence of global faith. Rebecca's reliance on a divine force allows her to move into a stage of global faith; her dependence on a higher being empowers her to view her life in a confident and courageous way. She states she is not scared to die. It is Rebecca's global faith that gives her the power to defy death. Such an outlook enables her to go on and face the day in the midst of adversity and uncertainty. Diagram 7.10 examines coping mechanisms in Rebecca's story.

Diagram 7.10



### **April's Story.**

*In 1990 April was diagnosed with breast cancer. She was fifty-four at the time and underwent a mastectomy. In 1996 April had a serious car accident. It wasn't until she had a MRI that she was told that she had cancer in her spine. April had radiotherapy and went on a hormone therapy program. In 1998 April experienced pains in her leg that were later diagnosed as cancer. She again underwent radiotherapy treatment. April is married and has no children. She has been a member of a support group for three years, which she attends once a week.*

Prior to attending a support group, April suffered from a nervous breakdown. During this period April says that she was unable to engage in her world; everything surrounding her seemed alien, distant and foreign. April eventually saw a counsellor and from there she decided to become a member of a support group. The support group that April attends plays a significant role in her ability to remain positive about her illness. April believes that since attending these meetings she has gained more knowledge about treatment and surgical procedures. Knowledge pertaining to her illness has also generated a degree of confidence when interacting with medical professionals. April also likes the fact that in her support group she can identify with other women who really understand what it means to live with cancer. She explains,

Cancer can be a very isolating thing and you can feel very alone with it. I did at first and I think initially I wasn't given enough information about it and where to go and a lot of the things I had to find out for myself. Since being in the group and sharing things you become more knowledgeable and you feel in control. I don't understand a lot of it as I am not scientifically minded, but I know a lot more about treatment and things than I did before and I feel at least I can ask the oncologist intelligent questions. I think you should learn a bit about it. It is no use going along with it and not knowing what's happening which is what a lot of people might do. (L: 3713-3720)

April also values the friends she has made from her support group. It is not only the women who she interacts with at these meetings, but also their family members, whom she has come to value and care for,

The husbands of wives who have died have come to have coffee with the group. They seem to want to do it. We meet at the hospital and we always have a coffee in the cafeteria afterwards. A couple of husbands came which was nice so they derived some comfort from the group. We understood their wives. One of the husbands was left with three children and one girl in the group was very good to

him. She still keeps in touch with him, which is nice. It has sort of gone beyond the group. (L: 3721-3729)

In associating with women, their husbands and children, April establishes new friendships. Being able to support husbands of deceased members also gives April a sense of personal satisfaction.

Death was once a frightening thought for April. Fears of dying in excruciating pain, without dignity, were commonly encountered by April. Since attending the support group, April has managed to free herself of this fear. Through witnessing the deaths of her friends in her support group, April is aware of the power of palliative care in its ability to assist a good death. Further, having the opportunity to see how other women have coped with dying, April asserts, has helped her to realise that dying isn't always distressing, or tragic. April's thoughts on dying are noted in the passage below,

I was scared and terrified at how I might die. Not the dying, the how. And I think since talking about it and even seeing some friends die peacefully has helped. Because most of them have died peacefully. I had this awful fear of being in terrible pain and in agony and now I feel hope....It did kind of help me to face up to it. I try to go to these seminars and there is a lot of information. The self-help group gives you hope and you sort of realise there are people worse off than you sometimes and you see how they cope and that helps. (L: 3856-3864)

April appreciates the advice she receives in her support group. Members frequently discuss remedies to cure an upset stomach, or relaxation techniques to calm nervous tension. Whilst April comments that it is hard when women die, she believes that the positive aspects of attendance over ride the negative ones,

You sort of accept. At the moment I have been going for three years and there are only two of us left from the original eight and we have lost eleven members of the group. It is hard but somehow the benefits of being in the group outweigh that. I didn't think I could cope with that I was quite amazed at myself (L: 3680-3684).

Having cancer has been a positive experience for April. Many women interviewed have expressed a similar outlook to April believing cancer to be a wake up call to

what's really important in their lives. Prior to her diagnosis, April was caught up in busy schedules believing she never had enough time to fit everything in. Now she realises that life is limited and enjoying the moment is what really counts. Since her diagnosis April finds personal satisfaction in travel and enjoys visiting beautiful locations,

We decided that we would go to Canada....I got more out of travelling after my diagnosis. Everything is sort of heightened. I think you feel things more and you appreciate things more and when I was seeing things like the Rockies and Niagara Falls and San Francisco and all this lovely scenery I appreciated it even more. (L: 3763-3773)

April also links nature to spirituality. She states,

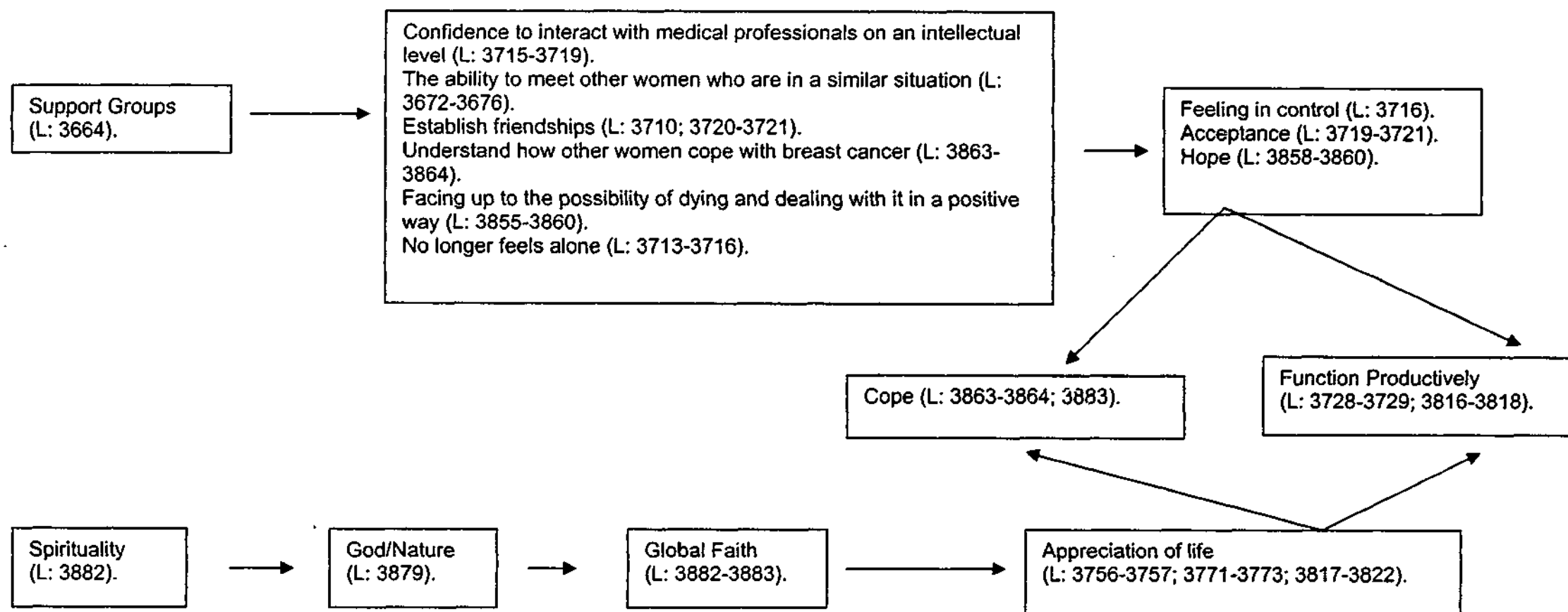
I suppose I would say I am not an atheist. I am an agnostic. I sometimes would like to have faith because I have seen some of my friends in the group who have strong faith and this helps them tremendously and in a way I sort of envied that faith. But I have come to the conclusion it is not me. I think I am a Christian and I suppose I have my own personal belief. I think God is nature. I think there is something because everything is so marvellous. I just can't accept this formal God. I think if I did it now I would do it for selfish reason just in case. I do think nature is wonderful and I see something in that. I feel that is quite spiritual seeing beautiful scenery. This makes me feel good inside. No religion hasn't helped me and I know it can but I think you have to be that way inclined anyway. Although I know a couple of people who took up religion and have found it comforting. I don't think I need it. I am quite comfortable. (L: 3875-3886)

In identifying factors that help April to cope, a number of aspects can be noted. Attending a support group is essential to April's emotional and psychological health. These meetings not only provide her with a wealth of knowledge, but also give her the courage to live. Further she has established a great network of friends whom she can ring up and rely upon. April's support group directly provides her with coping skills that allow her to function in a productive way.

While April sees herself as an atheist, she does have a global faith. In associating nature with spirituality and God, April believes in a sacred force. It is this belief that permits her to move into the dimension of global faith; her confidence in the world

and her surrounding environment precipitates a feeling of appreciation in having witnessed certain things. April says that since her diagnosis her perception of the world is heightened and she sees wonder in the historical places she visits. April comments, 'I feel good inside', when viewing spectacular cliffs or whilst taking in beautiful scenery. In being able to co-exist in such a way and in linking this feeling to nature, which she associates with God, April displays evidence of global faith. Figure 7.11 traces factors that facilitate coping.

Figure 7.11.



## **Carol's Story.**

*Carol was diagnosed with breast cancer in 1999. She was thirty-five at the time. As a result of her breast cancer Carol endured a lumpectomy and had five weeks of radiotherapy. She is currently in remission. Carol's mother died of breast cancer when Carol was sixteen. Her grandmother also died from this disease. Carol has a two-year-old son and is happily married.*

Carol reported that family and friends helped her to cope with breast cancer. When interviewed she told me that cancer had made her reassess everything in her life. Soon after her diagnosis, Carol came to realise the worth of family, which was something she had failed to consider in the past. Having sisters, who Carol could depend upon during her battle with illness, proved to be essential in her recovery process. Carol explains,

My sisters have become really important. Also I think I never had the roots of a home basis to go to. I had this incredible habit of picking up friends and using that as a parent like environment but drifting, going from group to group and now I realise that my husband has a wonderful strong family and I like being with them. I also feel that you can go over the top with family. I now know that I have a support network with people in the street. I would ask for help now if I needed whereas before I wouldn't. I was so depressed before and I would sit at the phone sobbing and I couldn't cope. It was self-destructive. (L: 2780-2788)

Carol also adopted a more selfish approach to how she chose to spend her time. Friendships she had established soon came under scrutiny when she was emotionally weak and vulnerable. Prior to her diagnosis, Carol would spend an enormous amount of energy on her friends at the expense of her own needs. Since her treatment, she chooses to establish friendships she can benefit from and dissolves those that prove detrimental to her health,

I need to rationalise my expenditure of energy. You are often very tired after radiotherapy and it is more important to look after yourself and those closest to you. Cancer has been a very powerful thing. And the other thing is I have two friends who I hardly ever see because my husband thinks they are painful. I think they are very nice people. I have a broad range of friends of different types of people. Anyway we hardly ever speak and when we do we get straight to the point, straight to the nuts and bolts and we talk about the most deep and meaningful things. This friend is very religious and I am not. She is always

making me think about things. When I come away from her I start confronting deep questions for myself. If she has the same problem she will definitely call on her religion to help her get through it. I haven't done that. I think I get through because I have a certain spirituality. (L: 2796-2813)

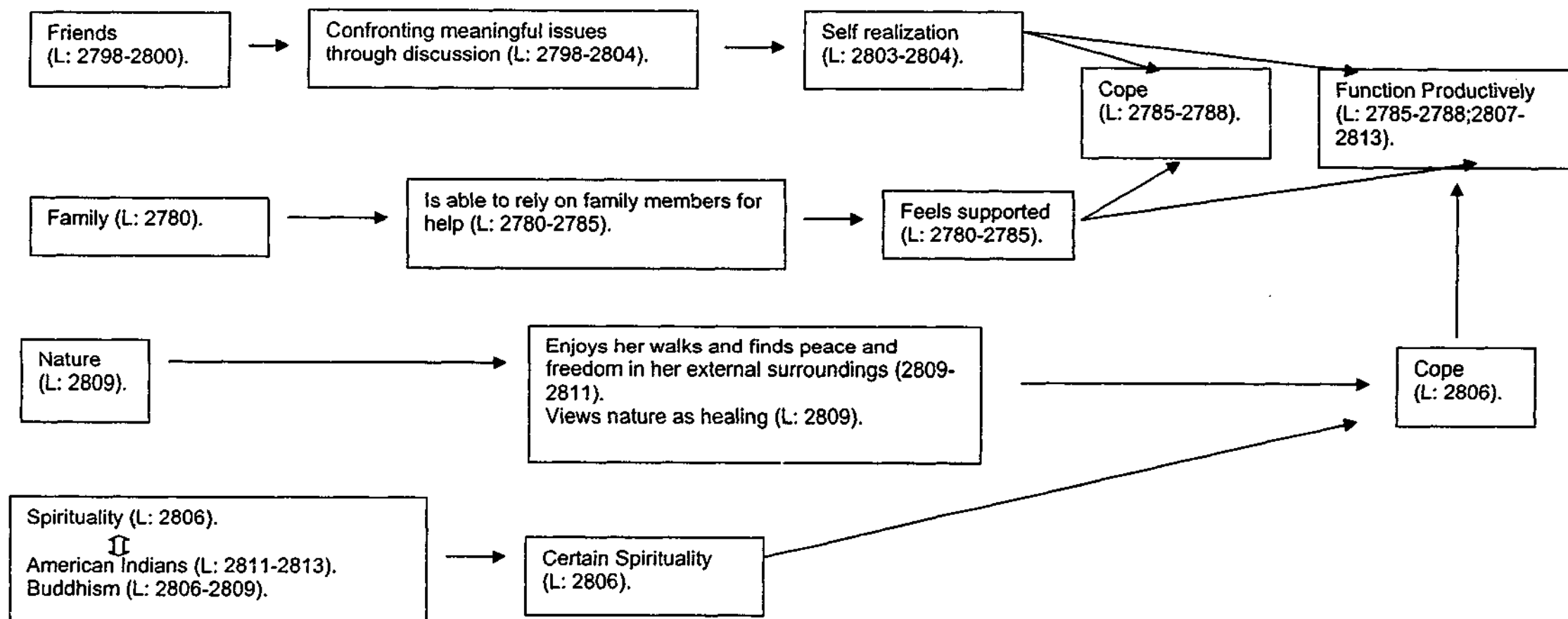
Carol also spoke of the importance of nature in her life. On this theme she says,

I am very big on nature and I am a bit more of a Buddhist if I am going to any religion. I have done some reading and I like what they offer and it makes more sense to me than my Christian background. So nature for me is healing. I feel claustrophobic at times and I need to get out in the open air. I am a country girl. I was brought up on a farm and I love open spaces and I think that is my spirituality. I have a great interest in American Indians and read a lot about their life and how they relate to the earth and their spirituality. (L: 2806-2813)

There is little evidence of global faith in this narrative. Carol depends upon a number of social support networks to help her cope with cancer. Her family and friends are important to her. In being able to receive emotional support from her husband, her sisters and neighbours, Carol feels secure. The positive energy that Carol gains from her network of friends and family assists her ability to cope. Being able to rely upon people who ultimately care about her personal welfare also sustains a positive outlook to recovery.

Carol discusses the importance of American Indians and Buddhism in her life. Yet, she does not rely heavily on these forces to reach a state of well-being. Rather, her walks in the open air, which she sees as spiritual, helps to precipitate a feeling of inner peace and happiness. In viewing her surroundings and her world in a confident way, Carol is able to cope with her cancer experience. Diagram 7.12 examines factors conducive to coping.

Diagram 7.12



### **Samantha's Story.**

*Samantha was thirty-two when diagnosed with breast cancer. As a result of breast cancer She had a partial mastectomy and has been in remission for three years. Samantha now suffers from lymphodema, a condition that results from the removal of lymph nodes. The removal of lymph nodes is a common procedure that takes place when women are diagnosed with breast cancer. Samantha is married and has no children.*

Samantha's experience in hospital was quite horrific. She explains her ordeal in the following way,

I shared the room with one other person. At the Hospital the staff looked like travellers. They had uniforms but they would come into the ward with leather around their necks and beads; they didn't look professional. They didn't even know what had happened to me, and what kind of surgery I had had. It was really strange...Once when the nurses had a changeover in shifts I had to tell the new nurse what to do. It was something really odd in that she didn't know where to put the needle. It was really strange. It was almost like they were temps and they had come from an agency. I remember one day they said, "Oh you can go and have a shower now". There was this drip stand that I was attached to. I said "How?" They said "Just take the drip stand with you". That was awful. I went into the shower and when I saw myself with all my bandages and stuff I just cried. I was so upset and I was just howling. Then they came in. I hadn't seen myself in the nude since the operation (L: 759-773). That was horrible because at that stage I didn't know what had happened. The surgeon didn't come back after the operation to tell you how everything went. All he said was that everything went well and then he left. The next time he didn't come, someone else came and it seemed confusing. Because the operation went well they thought I would cope. The support that they offered was next to nothing. The physiotherapist came around to tell me what exercises I had to do when I got home. She gave me a photocopy of some exercises I had to do; she didn't actually go through them with me and I lost the photocopy. (L: 777-784)

While professionals can be a source of strength and encouragement for many victims of breast cancer, in hospital Samantha felt completely alone. Her experience with the nurses and specialists further added to her anxiety. Yet, frightening of all was her vision of her naked body for the first time after her operation. She had no one there to comfort her when faced with the disfigurement of her breast and felt totally abandoned in her time of need.

Samantha eventually came to terms with her hospital ordeal. It took her twelve months before she was able to properly sleep at night. Part of her ability to move on

can be attributed to a Chinese doctor that she now sees. Samantha spoke of the importance of this doctor in her life,

I don't do meditation or relaxation. I have been taking Chinese herbs to clean out my system. The Chinese herbalist I see promises to get rid of my lymphodema. A friend of mine takes Chinese herbs and said I thought I should give it a try. Many people have recommended I do yoga, or meditation and that was so mind-boggling. I started to get depressed and overwhelmed by everything and I am sort of coming out of that now (L: 885-890). I started to get better because I think I had been through twelve months without sleep. The herbs after three weeks started to work and my mood just changed. I don't know whether it is the ritual of doing something that is good for you, but I stopped crying after two and a half weeks. Prior to this I used to cry everyday and I haven't really cried that much. Before I would spend whole weeks feeling sad and negative. So there has been a progression. (L: 893-899)

Samantha also spoke of her belief in guardian angels which has also helped to ease the terror she felt in the beginning,

I believe one of my spirit guides is a Chinese man. They say you have one that stays with you your whole life and then throughout your life you have others that come when you need them as they come with different skills. You can have a lot of them. They are like guardian angels and I feel a sense of relief. So that has always been my thing that has kept me feeling good. I do think that there is a bigger plan. (L: 925-930)

Since her diagnosis of breast cancer, Samantha believes her attitude to life and friends has changed. She no longer tolerates friends who cause her distress and will express her anger to those that show a lack of concern for her overall well-being. Prior to her illness, Samantha would put others first. Now she has taken a selfish approach to her time and her relationships with people. Her comments on friendships are noted below,

I guess the thing is I get frustrated with people who don't understand. I had some friends who behaved really badly towards me one night. I wanted to go to bed and they didn't want to go home. It was New Years Eve and a friend had brought over some of her friends. I was asking her politely to take her friends and go home and she wasn't ready to do that. I was so tired I turned the music off and said, "Right that's the end go home". They reacted so badly to me afterwards like I had let them down by kicking them out. I don't care any more. That was the first time in my life I had ever did that and I wasn't going to apologise. I thought they had been unfair. I am a much stronger person now. When you have cancer you have to confront yourself, what you think and what you feel. You have to take a lot more responsibility for what happens to you in life. If you don't like something you have to say no rather than complain about it. (L: 870-881)

There are a number of factors that assist Samantha's ability to cope with breast cancer. Samantha's belief that there is a Chinese spirit-guide watching over her allows her to feel confident about the world she lives in, a confidence that was absent during her time in hospital. Further her belief in guardian angels is part of her trust in a higher being. In believing in a divine force Samantha is able to move into a level of global faith. Samantha believes that her guardian angels are there when she needs them and they help her to feel 'good'. In feeling good about herself, Samantha 'feels a sense of relief'. She believes she is being protected from harm and suffering through the powers of these spirit-guides. This knowledge helps her to feel safe in her immediate environment. The ability to view her world in such a way is evidence of global faith. Samantha no longer cries everyday, but is happy to be alive.

Samantha sees the taking of Chinese herbs as being important in the healing process. This daily ritual gives her a sense of hope that she is purifying her body. Since taking these herbs she no longer suffers from depression. She reports that she started to get better once she began taking the herbs and this in turn allowed her to sleep at night. Her mood has changed since taking the herbs and she is no longer depressed (L: 895-899). A consequence of this is that Samantha is able to move on with her life and find peace within. There is no evidence of global faith here. The ritual of taking herbs directly helps Samantha to cope with a life threatening disease. In coping, she is able to remain positive about her future.

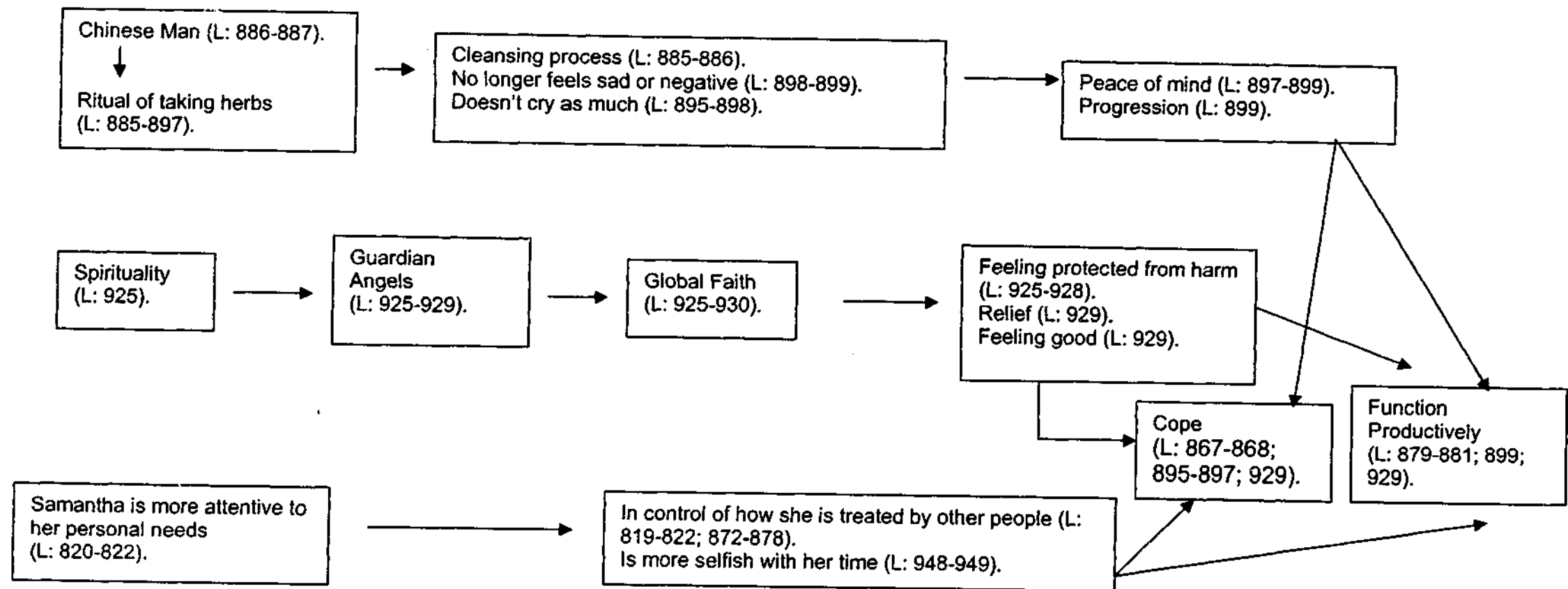
Samantha's comments that her attitude of becoming more 'selfish' to her own needs (L: 948-949) has helped her to value her life a lot better. Being selective as to how she wishes to spend her time and how she confronts issues in her life, help her to maintain a positive flow of energy. This is evident from her statement,

When you have cancer you have to confront yourself, what you think and what you feel. You have to take a lot more responsibility for what happens to you in life. If you don't like something you have to say no rather than complain about it

(L: 878-881). Now I find it difficult to trust people. I also blame myself for allowing people to affect me so much. I should have been more careful about myself and wary about how people were treating me. I can't believe I was so gullible. I can't afford now to give my care in the same way I did before. (L: 819-822)

Such an attitude helps Samantha to cope with her illness. She now has a different outlook to life which helps her to exist in a productive way. Diagram 7.13 below explores factors that facilitate coping.

Diagram 7.13



## **Tamara's story.**

*In 1995, prior to Tamara's thirty-fifty birthday, she was diagnosed with breast cancer. She has been in remission for three and a half years. Treatment for her breast cancer involved a mastectomy, chemotherapy and radiotherapy. Throughout the duration of her illness Tamara took photos. These photos were of her body before and after her mastectomy, her experiences in the hospital and her recovery following her operation. The main reason why Tamara decided to take such intimate photos was to help her remember her experience. Another reason was that she wanted these photos to be a source of guidance for other women who were faced with having a mastectomy. She believes that providing women with visuals of her experience would help them to understand the nature of the operation. Tamara has since given copies of these photos to the hospital where she received treatment and hopes to have them published one day. Tamara is married and moved to the country after her diagnosis.*

When Tamara told her boss that she had breast cancer he tried to fire her. She took her employer to the equal opportunity board and won. Having won her case she returned to work as she felt it important that she could still perform physical tasks following her surgery. As her job included cutting and lifting fabric, Tamara needed to prove to herself that she was still competent in her field of employment. After a short time she left to pursue a career in teaching. Tamara recalls this experience,

Once I told my boss about my cancer, he virtually tried to push me out. I thought, bugger this I am going to do something about it and I took him to the equal opportunity commission. I won, but it was all so stressful...One day my boss called me into his office and said to me, "You know you are going to die. My father is a doctor and you will die". These are the kind of people you don't want to be around. They want you to go away and disappear. Probably to this day they can't believe I am still here. (L: 1726-1735)

A social worker, whom Tamara had met in hospital, helped her during this traumatic time. Tamara reflects on the support she received from this woman,

When I was in hospital the social worker was quite good and I knew that if someone was going to give me a hard time I could ring her. The social worker knew all the legal ramifications which was necessary when I was treated badly by work. Not that she actually did a lot, but I knew she was there. (L: 1701-1704)

Being able to rely on a professional to help fight her case in court helped to reassure Tamara. This in turn assisted in her ability to cope with her experience of cancer.

Tamara wants to share her experience with other women who are in a similar situation. By using photos of her journey with breast cancer, Tamara believes she is able to offer some type of comfort to women who are uncertain of what to expect. Tamara also took photos to remember. Having pictures of her breast before and after surgery, alongside photos of her time in hospital, provides her with visual memories. Tamara explains,

I took some photos before I went into hospital and that was to get a shot of the boob before it was cut off. That's how it started and I just kept on taking photos after that. I took photos the day of the surgery and the next day after. I felt pretty good the next day. I don't look at these photos too much. It is good though because you don't have to worry about remembering. These photos are good for other people, as the fear is probably the worst thing. When I first was told about my mastectomy I thought well what is this going to look like? When you are in the trauma of being told, your memory is bad, but your visual image is better. I didn't have any visuals to look at. Having taken these photos I am able to help others. Now they use these photos all the time at the hospital because I have given them a set. I will do something with these eventually, perhaps putting them in a book just so people can see a visual image of people who go through it. (L: 1754-1765)

Tamara meditates and this helps her to feel in control. She does not have global faith, but believes she would become more religious if cancer returned. Practicing meditation is linked to a state of religiosity. She explains,

Others can help, but in the end it is up to me. I am trying to use this experience to become more focused, less stressed, more in control and more relaxed about what I can and can't do. I don't have a faith. I would say though that if I got really sick again I would become more religious, but I would use it in a sort of meditative way. I don't think there is a lot of difference between meditating and lying still and relying on God. They are both the same. Religion is only when you put a set of rules and images developed through a culture on a same plane. (L: 1807-1814)

Tamara sees God as, 'something that I can draw upon to give me strength' and believes that 'there is some power out there that we can all use' (L: 1824-1826).

In identifying factors that facilitate coping in Tamara's story, there is no evidence of global faith. Tamara's ability to cope with breast cancer has emerged from a number of sources in her life. There is the social worker who was familiar with the law. In

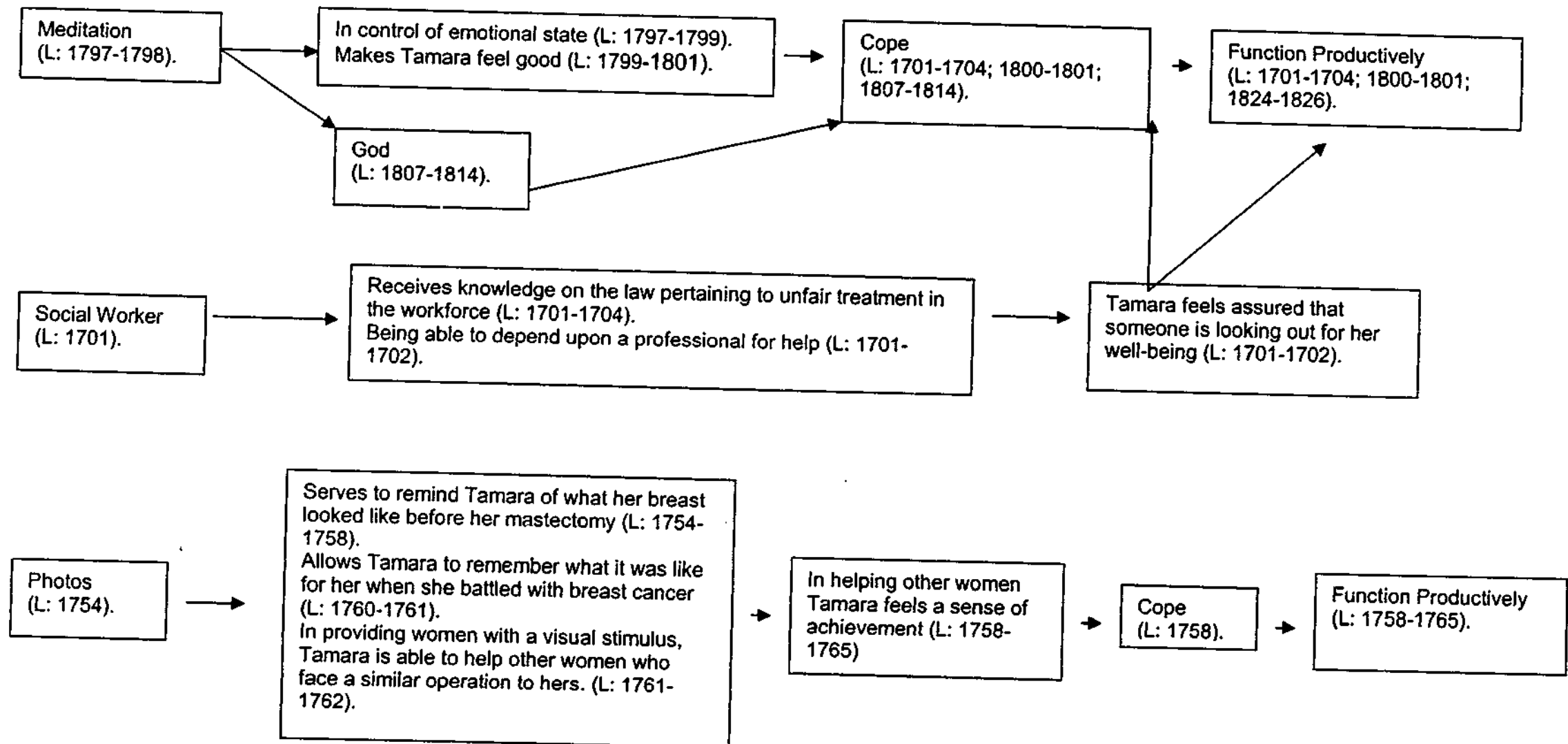
having someone to turn to during her ordeal with her employer, Tamara was comforted. In being supported by a medical professional she felt reassured when she took her employer to the Equal Opportunity Board that she was receiving expert advice.

Meditation is also a source that Tamara relies upon to attain a level of control in her life. During her treatment, meditation helped her to remain focused on her healing and this helped her to cope with her illness. Meditation is also aligned to a belief in God. Should her cancer return, Tamara is comforted in the knowledge that she will have a higher force to depend on for strength. Yet, this is not global faith, as she does not presently rely on God to achieve a state of personal well-being.

Tamara relies on her photos to remember her experience with breast cancer. In having visual images of her entire journey with breast cancer, she is able to trace her progression to recovery. Tamara also views her photos as a tool for helping mastectomy patients. She believes that her photos can help to relieve some of the fears and anxious thoughts women often go through prior to surgery. Being able to remember is important in her ability to move on and cope; being able to help others validates her experience and the tracking of her recovery.

Diagram 7.14 traces factors that facilitate coping in Tamara's story.

Diagram 7.14



### **Sharon's Story.**

*Sharon is divorced and lives with a boarder. She has a daughter and a grand daughter. She was diagnosed with breast cancer when she was fifty-six and has been in remission for three years. Sharon had a partial mastectomy but suffered complications following this operation. She is still in pain three years later. Sharon attends a support group once a week. Sharon has been a member of this group for three years.*

When Sharon was first diagnosed with breast cancer she explains, 'All I thought about when they told me was I won't see my grandchildren grow up' (L: 991-992). Sharon's role as a grandmother was very important in her determination to overcome her illness. Like the mother who does not want to see her children motherless, so too is the case of the grandmother who wants to be there for her grandchildren, to watch them grow, to protect them from harm.

Sharon also spoke of the support she received from friends and family during her time in hospital. When undergoing treatment, her daughter and niece were two people she could rely upon for emotional support. Sharon believes that having people in her life who did not treat her as ill or diseased helped her to maintain an optimistic outlook to her recovery. She states,

My daughter and her cousin and all the young girls were there and they took me there and that was the most beautiful thing. At that stage that's when you need people there to guide you, people who care. That's the most important thing people caring. (L: 1035-1038)

It was important for Sharon not to be treated like a victim during her illness. She did not want pity. Her daughter's outlook to her illness helped Sharon to feel 'normal'. We see when she says,

Yeah and also my daughter didn't say, "Ohhhh how are you mum?" like that. She didn't dwell on it and still doesn't and I think that that has helped me a lot. During my illness she never once said, "Oh you poor thing". She is positive and doesn't treat me differently. (L: 1043-1046)

The need to not be labelled a sick person is important for many women with cancer. Labels attached to illness can often serve to damage the self-esteem of the victim which can in turn hinder recovery.

Sharon commented on her relationship, following her operation, with the sister in charge of the hospital. According to Sharon, the sister in charge encouraged her, alongside other women in her ward, to remain positive about issues pertaining to body image. In being forced to reflect upon their scarred bodies, she was able to negate destructive feelings she may have had towards her breast. Sharon reflects on this time,

One of the nurses in the hospital used to say to some of the patients, "When you get up in the morning say, "I am beautiful". Look in the mirror and say, "I am beautiful". She was a fantastic lady. (L: 1058-1061)

The sister in charge not only worked on women's attitudes towards body image but also educated breast cancer patients in the ways to manage their treatment. Sharon discusses the importance of being knowledgeable about the kinds of questions to ask medical professionals so as to ensure her physical safety,

She was helpful in telling me things that I don't think a lot of patients get told. A lot of surgeons don't really know much about lymphodema, even the medical people. Like you go for a blood test and I tell them not to take it from my left arm. And they look at you as though you are stupid. I have to then explain to them that I have no lymph nodes in my left arm. But they should know and question this, but they don't. A lot of girls who have gone to hospital after their operation have had to fight with nurses in the hospital. Some nurses think it doesn't really matter and it does. With the lymphodema you have lost all your protection in your left arm so it can be dangerous. (L: 1065-1073)

Being physically active and doing the gardening also helped Sharon to cope with breast cancer. Sharon walks two kilometres every morning on her own and has done this for about six and a half years. During her walks, Sharon enjoys the scenic views of her area and is able to forget about her worries. As Sharon puts it, 'I love looking at gardens and houses. You can turn off from everything' (L: 1051). In being able to

focus her thoughts on other things besides her illness, Sharon is able to take a break from anxious thoughts and worries.

There are a number of factors that assist Sharon's ability to cope with breast cancer. Her daughter and her niece are important in allowing Sharon to feel comfortable about her illness and treatment. Sharon is happy that she is not treated in an abnormal way and this assists in her ability to cope. The sister in charge can be linked here. The sister, like Sharon's daughter, revitalises Sharon's spirits and brightens up her day. In being told to stand in front of the mirror and say out loud, "I am beautiful", Sharon is reassured that beauty is apparent even when a breast is cut off and mutilated. Further, the sister in charge informs Sharon about treatment, notably lymphodema. In being taught the right questions to ask, Sharon feels in control of her recovery and her overall health.

Grandchildren are mentioned in Sharon's interview. In this instance her grandchildren facilitate a will to live, which is in turn is linked to coping. Sharon's wish to be there for her grandchildren and to watch them grow up strengthens her desire to live. Coping for the sake of others can be a powerful tool in rejuvenating a downtrodden spirit. It is the will to live that empowers her to cope and go on against adversity.

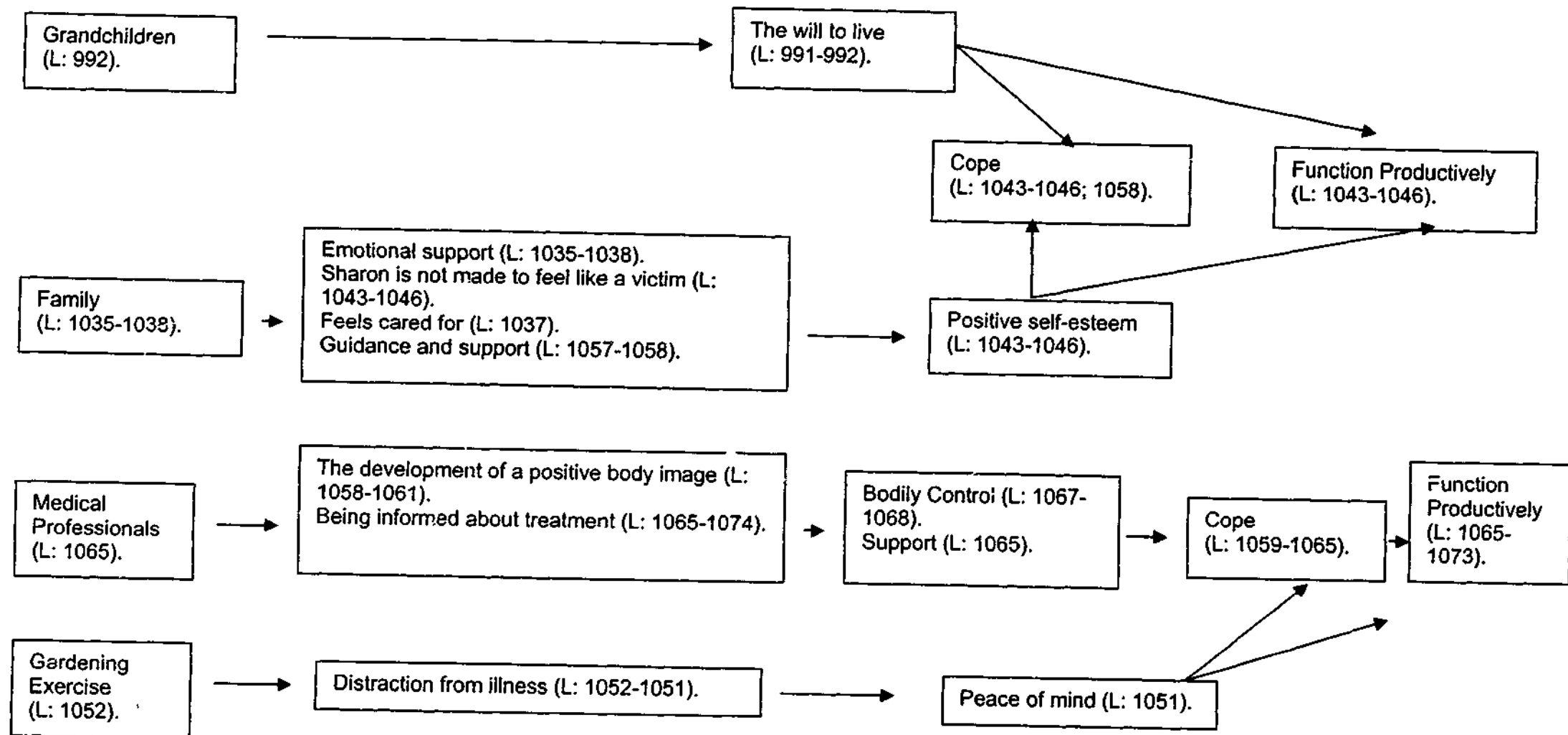
Gardening and exercise are important in Sharon's life as they help to distract her from illness. Having an outlet where she can focus on other things, other than being sick, helps in her recovery. In being able to enjoy her surroundings in the morning Sharon is able to begin her day in a positive way (L: 1051-1052). Walks help to clear her mind. Peace comes from focusing on the scenery of her outside world. Remaining physically active also strengthens a calmness within that has its origins in a belief that she is looking after her health. Many women interviewed similarly

witnessed this state of tranquillity when partaking in yoga and meditational exercises. Mind, body and spirit are therefore linked to coping and existing in a functional way.

While Sharon does not mention having a spiritual belief she does discuss the impact of human support in her life. During her stay in hospital she was fortunate to have developed a relationship with a nurse who encouraged her to feel good about her appearance. In being asked to view her body in a 'beautiful way', Sharon is able to feel a sense of comfort within. Further, her daughter and family helped her to feel loved and cared for. In being surrounded by loving people, Sharon was able to view herself as a survivor rather than a victim.

Sharon's ability to cope is not reliant on global faith. Her positive attitude to recovery comes directly from her family and friends, her grandchildren, medical professionals and her walks. Diagram 7.15 below traces factors facilitating coping in Sharon's story.

Figure 7.15



### **Beth's Story.**

*Beth is eighty-one years old and is a widow. In 1965 Beth was diagnosed with a malignant tumour in her breast. She had a lumpectomy and required no further treatment. Twenty-one years later Beth found another lump in her breast. This proved to be malignant and this time she had to have a mastectomy. Beth was sixty-seven at the time. Since this operation, Beth has been in remission for thirteen years. She attends a support group on a weekly basis.*

Beth is not religious. In her words, 'I live for today and feel o.k.'(L: 1187). Each time she was diagnosed with breast cancer Beth felt confident in the medical treatment she received. Not having to undergo chemotherapy, or radiotherapy also helped in her recovery. Beth explains, 'I didn't have to have any further treatment or chemotherapy or anything like that. He said he got it all out so that made me feel confident' (L: 1142-1144).

Beth's husband was also supportive during her illness. At the time they had been married for forty-four years and had a solid relationship. Beth attributes her age as being a key factor in accepting her mastectomy. She explains,

I feel very sorry for the young ones. With me, my husband was ten years older than me. We had been married for forty-four years at that time and we had a very good relationship. Our sexual life was beginning to diminish as it does with old age and it didn't bother us. My husband would always say, "Nature takes away from women child-bearing because it would be a danger to her and it takes away the ability for men because it could be a danger for them". (L: 1158-1163)

While in hospital a second time, Beth received support from her daughter and son-in-law. They regularly came to visit her and it was during this time that she felt loved and cared for. Beth comments on her daughter's reaction to her mastectomy, 'My daughter says to me, "Mum I never think of you as having one breast", so my appearance doesn't give that impression' (L: 1141-1142). Being treated as a whole woman was important to Beth and her recovery.

Following her release from hospital, Beth also had a close friend who would take her out for drives on the weekend. They would stop somewhere to have a cup of tea and enjoy the scenery. Beth appreciated these outings and this helped her to maintain a positive outlook to life. Beth says, 'my neighbour used to take me out for a drive and I had to sit with cushions because I couldn't bear the vibrations of the drive. I enjoyed the drives with my neighbour' (L: 1218-1220).

Beth has come to the conclusion that if cancer were to return, she would not seek further treatment. In her words,

Yeah I have had two more lumps taken out of my breast, but they have been benign. Every year for the last ten years I have gone for mammograms and checks, but I am not going any more. I don't want to know. I am eighty-one and I say let nature take its course. If it is or isn't, it is up to nature. (L: 1115-1118)

While she has taken this outlook to cancer, she regularly attends a breast cancer support group. Beth feels a sense of satisfaction when helping other cancer survivors. She tells me,

I like to go to the meetings for the younger ones who have breast cancer so they can see an older person who had it and got over it. I want to give them encouragement. I have been going there for I think eighteen months. (L: 1152-1154)

Beth attends a support group on a weekly basis. Her support group regularly organises social functions which she enjoys participating in. Beth states, 'I enjoy the social things we do. They have little outings. I think we are going on the 20<sup>th</sup> of June to a restaurant by the beach for afternoon tea' (L: 1229-1230).

There are a number of factors that facilitate Beth's ability to cope with cancer. Beth's husband supported his wife's surgery and assisted her in coming to terms with her mastectomy. In having a husband who did not treat her in a different way, Beth was able to move on with her life. In having a partner who she could openly discuss her

fears with, she felt comforted and secure (L: 1158-1161). Good communication between husband and wife is therefore essential to recovery and healing.

Beth's children also displayed love and care during her battle with breast cancer. Her daughter viewed her in the same way following her mastectomy and even verbalised her thoughts that she didn't think any differently of her mother. This helped to improve Beth's view of her deformed body. Having an understanding daughter therefore assisted coping.

Attending a social support group helps Beth to feel wanted and needed. In being able to share her story with other women, she believes she may be able to help other women who are experiencing pain associated with a diagnosis of breast cancer. Beth also believes her age is important in that she wants to offer hope to younger women who may be uncertain of their future (L: 1152-1154). Further, in attending a support group she is also able to regularly go on outings. These outings allow her to socialise with other women and establish new friendships. While Beth began attending this group some years after her diagnosis, she values the help she can give to others and the time spent with women who share a similar story.

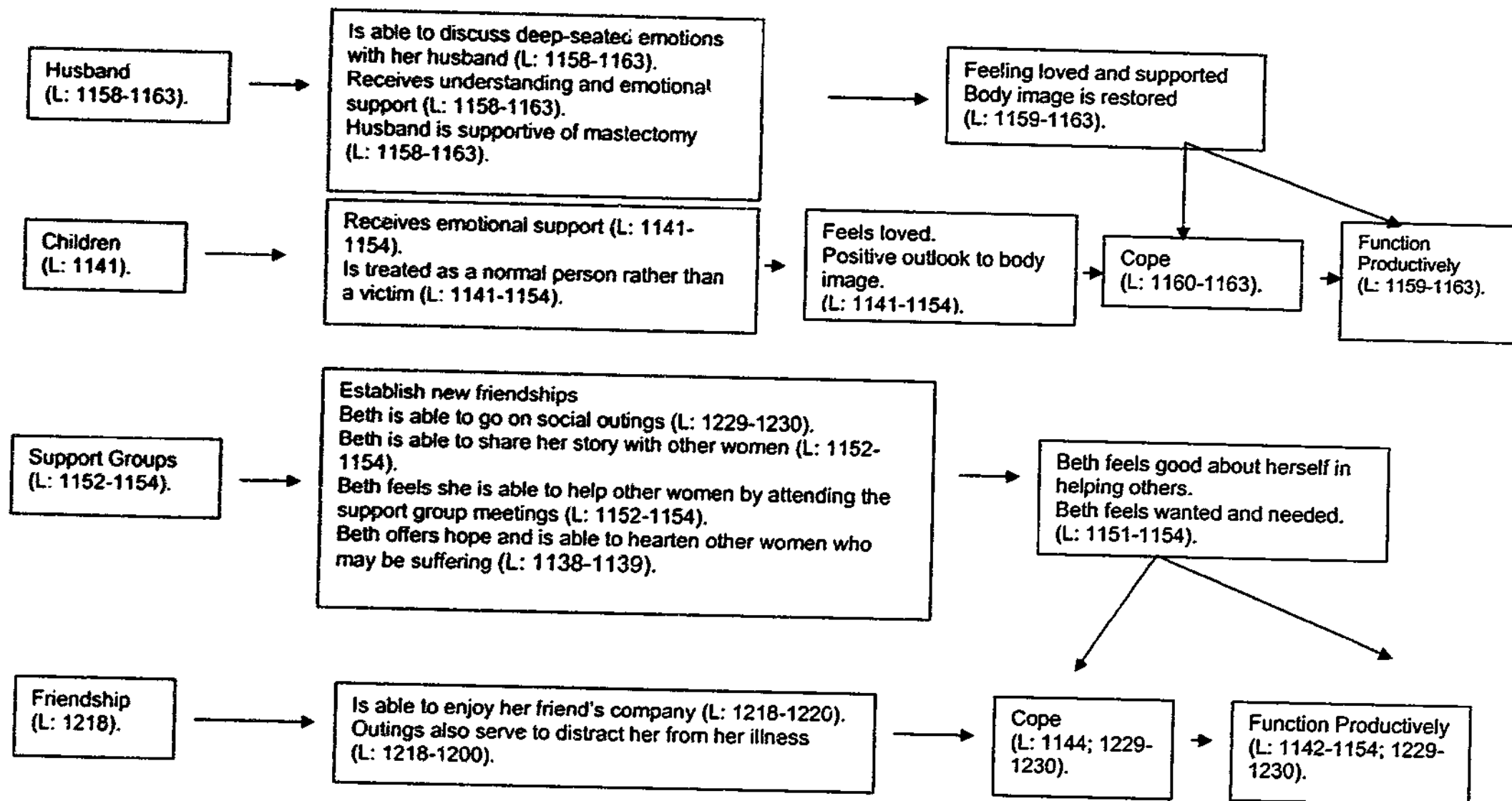
In having a doctor whom she truly trusted Beth was confident that all the cancer had been removed. This allowed her the confidence to move on with her life. Trusting the medical skills of her specialist facilitated a positive outlook to recovery. Coping can be linked to Beth's relationship with her doctor and her belief in his competent abilities as a practitioner.

Having a friend who would regularly take her out was important for Beth. In being able to go on drives with a friend she could talk to and have a cup of tea with facilitated an ability to cope. The outings also provided Beth with a nice setting in

which to focus her attention on. Outings were therefore important for restoring a sense of normality in her life (L: 1218-1220).

There is no evidence of global faith in this story. Beth is able to cope in a productive way through the various support networks she comes into contact with. Diagram 7.16 traces the factors that facilitate Beth's ability to cope.

Diagram 7.16



## Kay's Story.

*Kay had a mammogram in 1997. It was discovered that she had a lump and she was operated on. In June 1998 another mass was discovered. Another operation was conducted and this time it was necessary to have her left breast removed. Kay underwent a treatment of chemotherapy for six months. During the interview, Kay stated that she also wanted her right breast removed in case the cancer returned. Kay is divorced, but is currently in a relationship. She has two adopted sons. Kay is fifty-eight years old and is disabled.*

Kay loves to sew and is a member of a sewing club. Whilst sewing she is able to forget about her worries and enjoy the company of other members in the club. Kay explains,

I sew and that makes me feel good and a bit active. I just love being able to sew. See I can sew and sew and I will look at the time and five hours have passed. I get out to my sewing club once a week. We have a 'chin wag' and it is like a social event. One of the girls was away for three months and she came back and she said that she missed it so much. And she said, "I love the way we talk with one another". When I have people around me I don't dwell on my problem. (L: 2231-2236)

The sewing club enables Kay to connect with other women on an emotional level. Being needed by others is also important and makes her feel special.

Kay also spoke of the support she had received from her eldest son over the years. While suffering from depression, her son was there to give her the support and love she needed. Before her diagnosis of breast cancer, she had a serious accident that left her paralysed. In being confined to a wheel chair and in being restricted in the activities she can perform, Kay suffered emotionally. It wasn't long before she thought about committing suicide. Yet, it was her son who finally convinced her to seek professional help,

One day my son came home before he got married. That day I had thought seriously about committing suicide but didn't go through with it. When my son came home I told him about it. And he said, "Mum every time I come through that front door I wonder if you're still with us. When I leave for work you're sitting there watching television and when I come home from work you're sitting there watching television. I am sick of it and if you don't get off your fat backside you will be six feet under. What you need to do is you need to get to some rehab". I was crying and he was saying, "there is no use crying to me", he said. Anyway he found out who to see and I met this guy and I fell in love with

him. So I was in rehab for a month and I improved dramatically. I had a psychologist, physiotherapy, occupational therapy, hydrotherapy and I loved being there. I have been going there for eight years and I really feel that if I don't go there I will really drop dead. (L: 2238-2250)

Kay also attends a support group. Through her support group she is able to express her fears relating to death and dying. She also appreciates the knowledge she gains from other members in the group. Quite often guest lecturers will be asked to give seminars on issues to do with body image and treatment. Kay enjoys listening to these speakers and appreciates the encouraging advice they give to members in the group. She explains,

I think that the self-help groups are good because we are able to talk about stuff. We have guest speakers and lecturers. One lady was from the anti-cancer council and she came to talk about sexuality and she was wonderful. She was lovely and she was saying what you have to do is say three things you like about yourself when you get out of bed in the morning. And I was thinking three things, God I can't even think of one thing. Then she looked at me and she said, "Kay I have seen how old you are and you know what you can say, I haven't got a wrinkle on my face". I thought about this and thought how nice. (L: 2252-2259)

Targeting issues linked to body image helps Kay to focus on her attractive characteristics. She is encouraged to view herself in a positive way. Kay feels special when she is told she has no wrinkles and this helps her to remain positive about her facial appearance.

Kay cannot look at her naked body in the mirror. Her partner has never seen her naked. Yet she discussed the first time he touched her. She had been with her partner for ten months when he unexpectedly touched her breast. Kay spoke about the shock she experienced at having been caressed in an area she was ashamed of. In her state of shock she began to cry,

I can't think when it was that he touched me and I started crying. He asked me why I was crying? I told him that I was shocked he did that. He said, "It feels lovely don't be silly". He is a very nice man. (L: 2167-2169)

Kay's boyfriend helps her to feel that there is nothing abnormal about her body, even though she is ashamed of it. A partner, who does not turn away in disgust at the sight

of a deformed breast, who willingly touches it with affection and care, can help to destroy negative attitudes tied to body image. Feeling wanted by her partner in a sexual way helps Kay to reconstruct and repair shattered notions linked to her sexual identity.

Kay wears a healing crystal on her neck. An American Indian gave this crystal to her when she was in America. She explains,

When I went over to America about five years ago an Indian chief gave me a stone and it is supposed be a healing stone. He actually gave it to me when he saw how I was. When I came home I had it made into a necklace. He said that if I wear this stone it will help to take away the pain. And I have actually only taken it off a couple of days ago because it was hurting me in the night. But, since then I started becoming very interested in the American Indians. (L: 2206-2215)

Finally, Kay is not religious but she prays every night. Kay tells me that her life has been miserable and tragic. It was only when she started to really value living that cancer appeared. Kay believes God is responsible for her cancer,

It is as though God is saying, "Well she is getting by with everything else, let's give her something else to give her problems". But you know I have always prayed to God every night. I never prayed to God for anything to do with me. I don't mention my cancer at all. (L: 2184-2187)

Kay therefore looks upon her illness as a punishment and believes that she is destined not to live a happy life.

In identifying factors that assist coping in Kay's narrative, there is no evidence of a global faith. Through various other sources she is assisted in her ability to cope with the disease. Kay relies on her son and partner for emotional support. Through these two important people in her life, she gains the courage to face the day. Her partner encourages her to view her body in a positive way. Negative perceptions tied to her body can be dealt with when she is shown love and acceptance. Kay's son is also a key factor that facilitates a desire to live. In no longer wanting to commit suicide

because of her son, we see a will to live. Kay does not want to put her son through the pain and torment of her death so she chooses life.

Sewing is important to Kay in many ways. In attending a sewing club she is able to interact with other women who share a similar interest. She feels wanted here and encounters a sense of belonging. When women also express their need for her company Kay is happy. Further, her sewing is a distraction from her illness. Some women have spoken of other distractions in their lives such as gardening, or travel. For Kay, sewing preoccupies her with thoughts other than her illness. Finally, Kay's network of friends in the club, provide her with a sense of identity. She no longer feels isolated in her pain and no longer relies on a television for company. Sewing connects her to people and this gives her something to look forward to. Sewing makes Kay happy and this helps her to cope.

The support group that Kay attends allows her to interact with women who have also experienced breast cancer. Being able to discuss her concerns attached to her disease helps to address deep-seated problems within. Further, having a speaker at her group, who focuses on body image, provides Kay with an opportunity to reassess her physical appearance. The encouragement she receives from the speaker assists in strengthening her self-esteem and this facilitates coping.

Attending a rehabilitation group is also valuable to Kay's recovery. She states quite clearly, 'I feel that if I don't go there I will drop dead' (L: 2249-2250). The rehabilitation centre helps to rebuild her emotional, physical and psychological state of being. This in turn assists in her recovery. Diagram 7.17 examines factors that assist coping in Kay's life.



## **Jane's Story.**

*In 1994 Jane was diagnosed with breast cancer. She was fifty-three at the time. The test results indicated that there was cancer present in both of her breasts, which resulted in her having a double mastectomy. Jane now has advanced cancer, but is still hopeful of recovery. Jane has children and is a grandmother. Jane commented that if the cancer were to render her dependant on others, she would attempt suicide.*

Jane reflects on her time in hospital with fear and dread. Her arms were totally paralysed when both her breasts were cut off. As a result, Jane was forced to depend on the nurses for assistance and for the first time in her life she felt completely vulnerable. There were also machines that were hooked up to Jane's body. One machine monitored the amount of morphine released into her bloodstream, yet the pain of her operation was at times unbearable. She talks about her stay in hospital,

I couldn't sit up to even cover myself. For the first time in my life I was to know complete dependence on another human being to help me. It was unbelievable. I will never ever live in such a state again. I would prefer death to helplessness and I will commit suicide, if ever I have an illness that renders me helpless. To get my arms back to normal I had to keep trying to raise them and with exercise I gradually got them back to normal. That restored my dignity and independence. (L: 3232-3238)

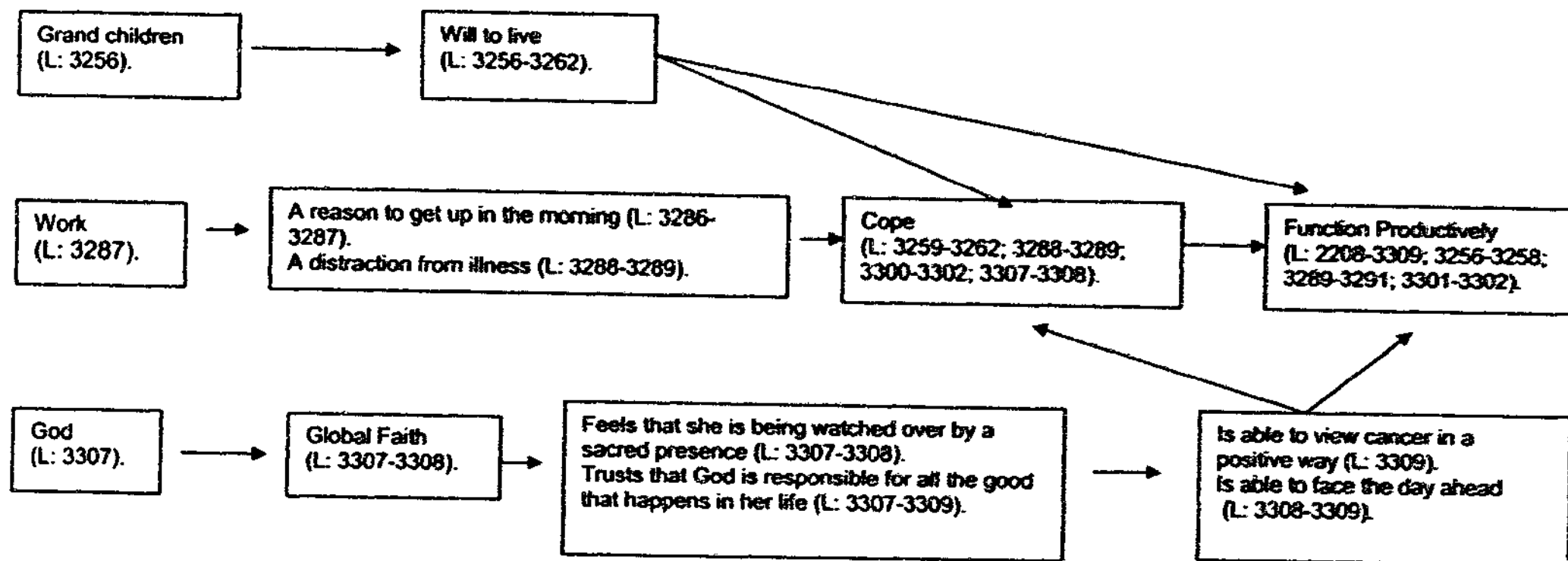
Jane cannot look at herself in the mirror and her disgust at her body has meant an inability to have a relationship with a man. She asserts,

I think the only aspect I can't deal with is an invitation from the opposite sex to go out. All I can think of is I'm this freak of a woman without breasts and how do I explain that my flat chest has two huge scars right across it? I can't solve it even when I admit to breast cancer. I don't think it occurs to people that a woman has actually had her breasts off because of cancer, so I don't go out with the opposite sex. (L: 3243-3247)

Yet, whilst she views her cancer in such a negative way, she does speak of how important her role is as a grandmother. Her grandchildren are a motivating factor for her wanting to recover from her illness,

Another thing I do is to think about my grandchildren. My granddaughter Naomi is very precious to me. Whilst my daughter has helped me with my illness in so

Diagram 7.18



## **Lisa's Story.**

*Lisa was diagnosed with breast cancer in July 1997. She was forty-nine years old at the time. Her treatment involved a mastectomy, chemotherapy and radiotherapy. Lisa is in remission and remains positive about her cancer. She is divorced and lives on her own. Her daughter and son live with her husband. Since her diagnosis Lisa has returned to study.*

Following her diagnosis with breast cancer, Lisa decided to get a puppy. Having a puppy helped Lisa in a number of ways,

I got a puppy. My dog was something positive and really good for all of us. I take him to the beach most days for exercise. What one should do is get out and exercise. Having a dog forces you to exercise. I take my dog for walks down to the beach and I do so enjoy the beach. It is almost like meditation. I mean I went to meditation classes and stuff like that, but just walking on the beach is lovely and so relaxing. (L: 2600-2603)

She also took up swimming following her diagnosis and believes that this activity allows her to relax and unwind from the pressures of her day (L: 2564).

During her illness, Lisa attended a support group and found this experience to be important in her recovery. At the support group, she was able to discuss her emotions evoked by breast cancer and was able to obtain information pertaining to treatment and care. Her thoughts are expressed in the following passage,

Initially I went for me and it was really good just hearing how other people were dealing with things. It was also good hearing that they had problems too because I kept thinking the way I was feeling was my entire fault. So I think that understanding that I wasn't the only one going through it really made that difference. (L: 2600-2603)

Lisa's relationship with her father has improved since her diagnosis. She now has common interests with him which include walking their dogs on the beach and being members of the local yacht club,

Now things are better. I am now the treasurer for the local yacht club because me father asked me to do that. I think we need a quest in life, something that will make you feel that you have achieved certain goals. (L: 2618-2620)

Lisa also returned to study after her diagnosis of breast cancer. She tells me, 'I decided to go back to uni and do something I enjoyed. So I went back to study and I am sure the study did help me to get better' (L: 2573-2575).

Lisa sees her breast cancer as contributing to a loss of faith, mainly a loss of faith in people. Her reasoning behind her faith stance is attributed to how she was treated by others,

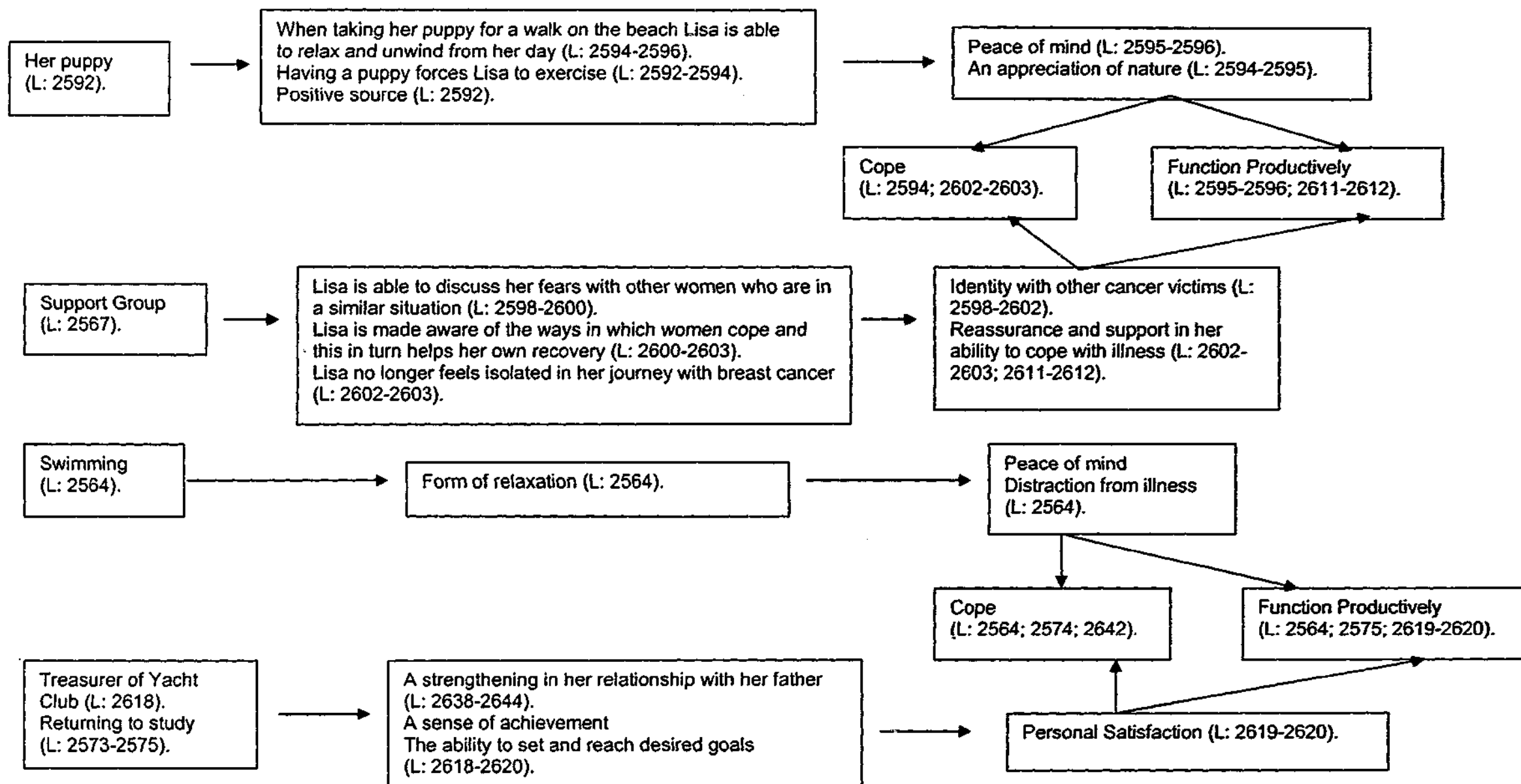
I think I had a loss after breast cancer. The reason being people I came across didn't really care what was happening to me, or other people. I just think we need to encourage people to do things for each other, look after the environment that sort of stuff. I don't have belief in a higher being. I believe if I died tomorrow my reincarnation to me means what the people I leave behind remember about me. So I have to make sure that what I do is worthwhile. I don't want them to have negative memories of me. As a mathematician I know that we live in a world that we don't understand and I have no idea what is beyond us. We can only understand what we experience so all our experiences should be worthwhile. (L: 2656-2665)

While there is no evidence of global faith in Lisa's story, her ability to cope with breast cancer can directly be related to various sources and social networks. The support group that she attended allowed her to identify with other women who were experiencing similar problems. As a consequence of this, Lisa no longer blames herself for the way she feels and does not feel alone in her suffering. This outlook to her illness helps Lisa to cope and manage destructive emotions. Having had the opportunity to tell her story has assisted in her recovery.

Lisa speaks of the need to achieve goals. Her desire to accomplish set tasks was the motivation for returning to school. In becoming the treasurer of the local yacht club, Lisa has a sense of purpose. A desire to fulfill certain expectations can be linked to a feeling of confidence in her world. Yet, this is not evidence of global faith. Lisa does not depend upon a sacred force to improve her outlook on life, but relies on other factors to function productively.

Swimming and taking her puppy for a walk are a form of meditation for Lisa. In participating in such activities she is able to unwind from a busy schedule and relax. Walking on the beach and swimming help her to attain peace and serenity; such emotions facilitate coping. Further, Lisa's puppy is a source of positive energy that motivates her to exercise and enjoy the beach. Here we see how animals can also play a role in the coping process. Diagram 7.19 traces coping mechanisms in Lisa's narrative.

Diagram 7.19



## **Fran's Story.**

*Fran was fifty-four when she was diagnosed with breast cancer. She is now sixty-one. She has fourth-stage breast cancer, the most advanced stage of this disease. Currently she is receiving chemotherapy. When first diagnosed with breast cancer, Fran had a left-modified radical mastectomy. During the operation, it was discovered that Fran also had cancer in her right breast. Further, she was told that it had spread to ninety percent of her bone marrow. Adding to this, cancer was detected in the right bone of her pelvic hip. Whilst radiotherapy helped to clear up the pelvic hip, it has since returned to her bowels. Fran is married and has a daughter and a son. She regularly attends a support group on a weekly basis and enjoys spending time with her friends and family.*

Fran's support group is essential in providing emotional relief. According to Fran, attending a support group is the best thing that has happened to her. Here she is free to discuss her fears and anxieties without the worry of upsetting people. In being 'in the same boat' as other women, Fran has also established a network of close friends whom she can rely on during times of despair. Fran tells me,

That was the best thing that happened to me because we don't have to protect anybody because we are all in the same boat and we have become a very close unit; we are all good friends. There are social activities outside our support group. We ring each other up and it really is a worthwhile experience. I wouldn't be as good as I am now without it that's for sure. So I think you need support from your family, which is really most important, but then you also need to be able to express yourself outside the family. (L: 30-36)

This support group also helps Fran to not fear the dying process. In being surrounded by women who also face the prospect of dying, Fran understands that dying doesn't have to be a frightening experience. She has learnt that with the assistance of palliative care, dying can be pain free; awaiting death can also be seen as an opportunity when problems can be dealt with, feuds can be resolved and harmony restored. This is noted in the following extract:

I look at dying in a different way. It used to be absolute fear because I have seen my mum die due to a heart issue and it affected me enormously. When my half brother died that was very distressing as well. And I thought that was how everyone went. But, since I have belonged to the support group and had to deal with women in the same boat as me I have come to realise it isn't necessarily all that bad. What I have realised is that this is a time when you can really get your relationships together with your family and friends, put things in

order, no regrets. We have got time to do it and I am more aware of the support you get from hospitals in terms of palliative care. That makes me feel safe as well. (L: 126-134)

Prior to attending a support group, Fran felt completely isolated in her pain. She had no one, who truly understood the emotional roller-coaster she was on. Fran also felt uncertain of her future. Here she discusses the total despair she felt during this difficult time in her life,

I honestly think I didn't come to grips with it possibly happening to me. So I remember being in the house alone about four months out of hospital and I broke down and I cried and I cried and I felt so desolate and so alone and I thought what am I going to do? I didn't know what I was going to do? And at that stage this is going back six and a half years ago there weren't any breast cancer support groups. There were general ones and I didn't feel well and didn't want to go out. So there was no support, nothing at all except my family who were magnificent. Yet, sometimes when you're the victim you don't want to worry them with absolutely everything so I would watch what I said to them. In the process I felt very very alone. I remember that very clearly and I had the feeling that absolutely no one understood the extreme trauma I was going through. (L: 9-19)

Buying a new dog also helped Fran's to cope with her illness. Fran believes that her dog helped her cope with breast cancer by providing her with a great deal of comfort and joy.

I am absolutely sure he helped me with my coping. The love they give can mean so much at times. My husband noticed the dog adored me from the first minute, it was like a coming together. He is such an affectionate little thing who has given my husband and I enormous pleasure. (L: 80-83)

This unconditional love bestowed upon Fran by her dog provided her with a feeling of being needed and wanted. This helped to create a positive atmosphere within her household.

Fran returned to painting after her diagnosis of breast cancer. She finds this hobby pleasurable in that it keeps her mind away from her illness. Fran explains,

Another thing that has helped me is that I have always painted, but always in a slap dash fashion. I have been doing it probably since I was eighteen years of age but never really got into it. I was always too busy. But, when I had to give up work because of my treatment, I had a big void in my life. I remember one

day saying to myself, "What am I going to do?" I decided that I would start painting again. It allows me to express emotions about cancer. Initially I went to classes again and I totally lost myself for the two hours I was there. When you have cancer you can't help it. Cancer is always there at the back of your mind and it is nice to have relief from it. (L: 83-91)

Having a hobby whereby she was able to take her mind away from her illness helped to restore a feeling of well-being within.

Fran comments that she is not a spiritual person, yet does believe she achieves a spiritual dimension through God, friends and her family. She states, 'I am not very spiritual. I love life, I love animals and nature. Good friends and family are so important and that is where I get my spirituality. My belief is that God is goodness and there is goodness in people' (L: 134-136). Fran's reference to God as 'goodness in people' tells us that she sees a sacred force in the special individuals she comes into contact with.

There are a number of factors that facilitate coping in Fran's story. Support groups empower women to feel that they are not alone in their dealings with cancer. Through her interactions with other breast cancer victims, Fran is able to cope; she no longer feels isolated in her pain and suffering and is therefore able to remain positive about her recovery. Here she sums up this feeling:

After the initial fuss and bother when everyone comes to visit you, and you are like a celebrity, that does die down and then it gets quite lonely. That is when you need support. There was no interaction with the community, which I used to like. I am not the type who will ring anyone up when I am miserable, I never do that. Yes the group has been a very positive experience in this sense as I can ring people up from the support group when I feel down. (L: 116-122)

The support group links her to a state of existence that embraces her pain and uncertainty. Fran is able to enjoy life and is comforted by the presence of others who have adopted a positive approach to the breast cancer experience. Her support group is not tied to faith, rather it is an external source that leads her directly to

feelings of well-being. Prior to attending the group, Fran was overcome with grief and depression. Now she is able to appreciate the time she has left. She states,

I also love going out to dinner, theatre, and films. I am more appreciative of the moment now, whereas before I would have probably been very busy. I was a very busy person who tried to fit a lot into the day. Now I know I can just relax and stop and smell the roses. (L: 96-99)

Her relationship with her dog is also another factor that is not dependent upon faith. Fran's dog provides her with love and affection emanating a feeling of happiness and joy. Such emotions assist her ability to cope and function in a productive way.

Painting helps to distract Fran from her illness. She tells me, 'Initially I went to classes again and I totally lost myself for the two hours I was there. When you have cancer you can't help it. Cancer is always there at the back of your mind and it is nice to have relief from it' (L: 89-91). In being able to focus her thoughts on her artwork, Fran is able to think about pleasant things besides her cancer. Fran also uses her paintings as a source to express her emotions tied to cancer (L: 88-89). The ability to release hidden tension and anxiety through her art helps her to cope with her illness. The ability to distract herself for a few hours also helps her to function in a productive way.

When Fran discusses the importance of God in her life, we see evidence of global faith. Fran believes that God is goodness and this goodness is witnessed in the loving people she comes into contact with. Her relationships with her friends and family are therefore linked to a notion of holiness. People, who are inherently holy, make her feel special and this helps her to view her life in a confident and appreciative way.

Diagram 7.20 traces factors facilitating coping in Fran's narrative

many ways, my granddaughter has provided me with a different level of support. Just watching Naomi's eyes light up whenever I enter the room and watching her run to me from the driveway, touches my heart. I love her to death and treasure those moments with her always and when I feel that life is too much and I would be better off dead I visualise her tiny, adorable face and know that this pain is all worth it. (L: 3255-3262)

Jane still works and has found this to be important in her ability to cope with illness. She states, 'I think it is good because I am still working, which means I have to get up, shower, dress up, put a face on and get to work. As a boss I am very busy and I don't have time to mope' (L: 3287-3289). Other sources of strength have been her support group, friends and family.

Jane does believe in God. As a child, Jane was very religious and this religiosity has carried on into her adult years. In feeling connected to a divine force, she feels watched over,

I always felt that the faith I had in God would always keep me safe and I still feel it now. For anything good that happens in my life I say thank you Lord, and somehow it hasn't occurred to me that cancer is bad. (L: 3307-3309)

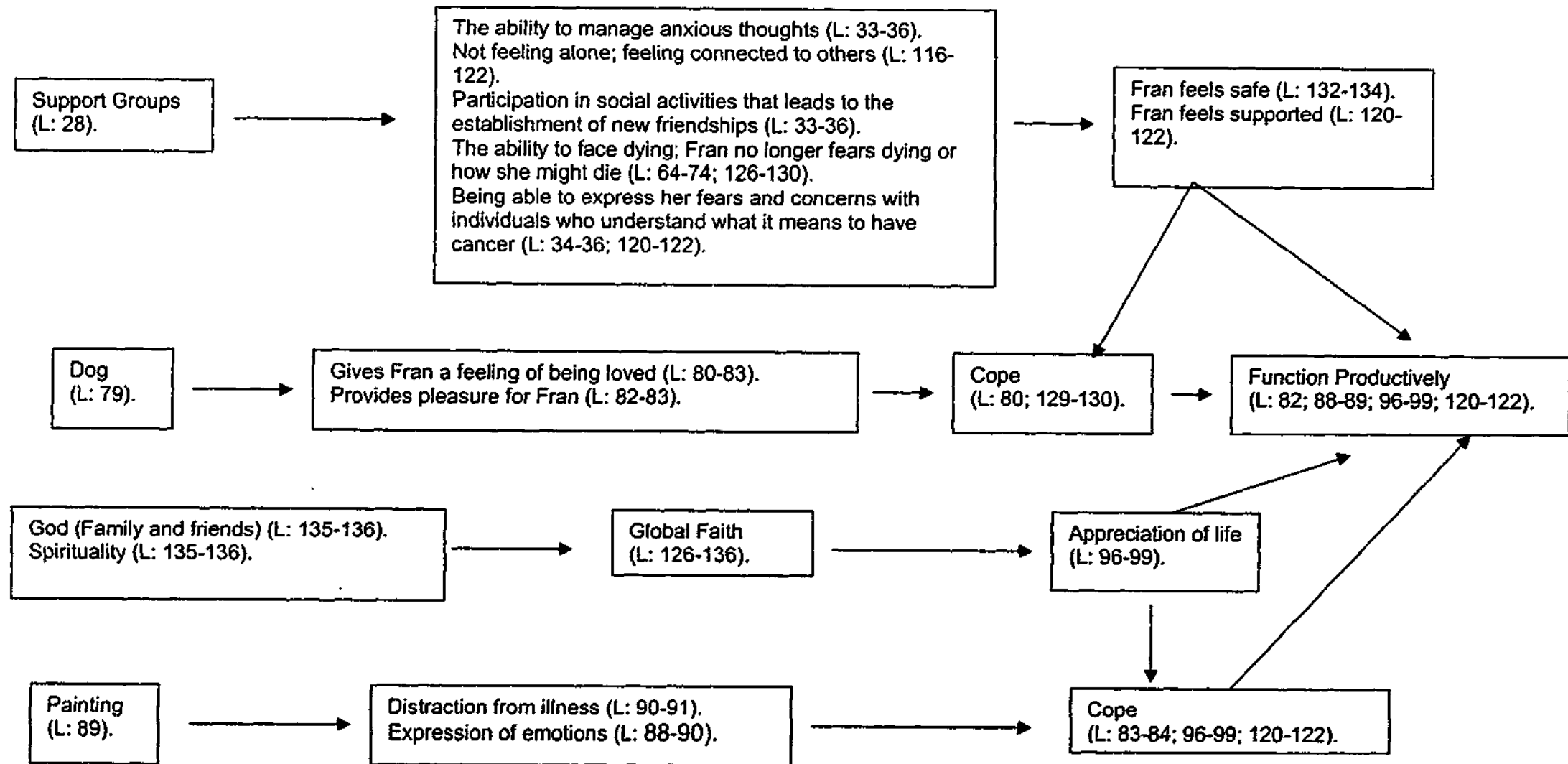
A belief in a sacred presence provides Jane with a level of comfort in that she feels a sacred being is protecting her from harm.

There are certain factors that facilitate Jane's ability to cope. Jane's grandchildren are a motivating factor for her determination to survive and facilitate a will to live. When her pain becomes unbearable, Jane thinks about her grandchildren and this helps her to remain courageous in her battle.

Work is important for Jane in that it gives her a reason to get out of bed and 'put on a face'. In being forced to go to work Jane is able to focus on other things besides her illness. Being busy and having a senior position at work has helped her to cope with her terminal condition.

A belief in God provides Jane with a belief that she is being watched over by a sacred force. It is this feeling that allows her to move into a dimension of global faith. Having a divine trust in a higher being is synonymous with having global faith. Trust and confidence in her world are also apparent in this story. Jane feels 'safe' because of her belief in God. The ability to view her world in a safe and confident way is evidence of global faith. Even though Jane has terminal cancer, her global faith empowers facilitates a feeling of security in her life. Diagram 7.18 traces factors that facilitate coping for Jane.

Diagram 7.20



### **Conclusion: Facilitators to Coping and the Role of Global Faith.**

Having examined the narratives of twenty women, coping with breast cancer can be seen to take a variety of forms and is not necessarily always reliant on global faith. Of the twenty women interviewed eleven were seen to embrace global faith in their stages of recovery. The remaining nine women looked to other sources in an attempt to accept and re-evaluate their illness.

Support groups were the most heavily relied upon source for women in this study who are coping with breast cancer. Eleven women reported that support groups contributed to their ability to deal with breast cancer in a productive way. Based on the narratives of these women, it can be said that support groups offer a variety of skills that assist in their dealings with disease and illness. Self-help groups educate women of the different treatments that are available to them. Victims of cancer, in self-help groups, often raise similar questions. Frequently asked questions involve; is radiotherapy an option to take in controlling breast cancer? Who is the best plastic surgeon to approach in the event of a breast/s implant? What diet best suites chemotherapy treatment? Where can I buy a wig that will fulfil my needs? What techniques can I depend upon to manage my physical and emotional pain? Listening to the stories of breast cancer survivors can offer possible answers to these kinds of questions.

Joel Nathan (1998), a survivor of cancer, writes about the importance of cancer self-help groups in providing assistance to unanswered questions. He draws attention to the value of attending support groups and meeting people who share a similar story. He writes,

Perhaps the most useful contribution of a group is that it provides you with the best opportunity to meet and talk to others who, like yourself, have come face-

to-face with a life threatening disease. In such a unique environment a fellowship is created, in which there are no distinctions of age, sex, social status or economic class. In a support group everyone is equal—as we all are in the face of suffering and death....Thoughts that are unexpressed race round and round in you head, go nowhere, and cause great confusion and distress. Talking it out can calm the commotion in your mind, help you come to terms with your condition, allow you to see yourself and your disease from different perspectives, and help you bring your body's own healing powers into play. (p.233)

Thus, women with breast cancer, who attend self-help groups, can benefit not only by telling their stories, but by also listening to how other women cope with illness. Assistance in relaxation, diet, medication, dealing with depression and pain can undoubtedly be provided in this kind of setting. Techniques in how to deal with the rejection of friends, family and work colleagues are given a considerable amount of attention in cancer support groups (Nathan 1998:232). Support groups are therefore an essential tool in providing emotional relief to women who believe that no-one can possibly understand their pain. Support groups also offer women with free counselling and medical advice and a chance to meet other women who share similar problems.

While family and friends were seen to be of great support, many women interviewed maintained the need to be honest with their thoughts, without the threat of causing distress upon their loved ones. Being able to honestly discuss their anxieties and concerns relating to living with breast cancer was essential for coping. Those women who were also worried about being gossiped about saw the support group as a place where they could express themselves openly. Support groups certainly provided a situation where many of the interviewees could bear their heart and soul without the fear of worrying people who did not understand the experience of cancer. Interacting with women who were able to be objective and offer sound advice was essential to healing and recovery. Overall the most useful contribution of support groups was that they provided a large portion of the women in my sample with the opportunity to

come face to face with other women who shared similar stories. Hearing about women who suffered worse fates than themselves, who still remained positive throughout their experience, inspired listeners to continue on with their battle despite the uncertainty of their future.

In chapter two, the question was raised as to the importance of support groups as a coping tool in the lives of women with breast cancer. According to Durkheim (1965), forces of social integration bind people to a collective consciousness. The greater an individual's sense of belonging and unity with other members of society, the greater are his or her chances of dealing successfully with crisis. Support groups can be seen to embrace Durkheim's view in that they provide women with an arena where they can share their fears and concerns with other women. In the process victims of cancer feel connected to a greater force. Support groups therefore allow women to identify with other women. In sharing their experiences within a caring environment, women no longer need to feel isolated or alone in their suffering.

Another common coping strategy outlined in seven of the interviews was a reliance on God. God was sought through prayer, church attendance, meditation and spiritual rituals. An Australian Community Survey conducted by researchers from Edith Cowan University concluded that, 'One in three of all Australian adults say that the desire for a spiritual life is very important or the most important principle guiding their lives' (Hughes 2000). Over half the women in this research relied on global faith to maintain an optimistic outlook to their recovery. Those women who prayed saw prayer as a special time when they could express their needs, thoughts and fears associated with breast cancer. Further, prayer provided women with a sense of being watched over by a higher being, or a divine power. Other emotions associated with praying involved a feeling of being heard and understood by a divine being. Prayer

therefore served a variety of functions for women. These included, a need to feel closer to God, a desire to find peace within, a hope that God would intervene and heal them and a trust that God would carry them through their ordeal. Thus, women, who spoke of God in their narratives, depended upon a sacred force as a means of encouragement, guidance, healing and strength.

Nature, family, hobbies and meditation were relied upon by a quarter of the women interviewed. Those women who mediated saw the purpose of this activity as a means of achieving calmness and serenity in their lives. All the women interviewed believed that one of the hardest things when faced with breast cancer was the feeling that they had lost control over their bodies. The emotional impact that this had on their state of being was often immensely damaging and destructive. Meditation was a positive coping tool in that it provided a medium whereby minds could be controlled and altered. A state of existing that let go of dread and anger was acquired through meditational practices. Thus, meditation provided women with a sense of empowerment in that it allowed them to reclaim control over their thoughts and emotions. Meditation allowed women also to establish inner confidence about things that troubled them; negative thoughts were replaced with positive affirmations encompassing a feeling of well-being. Women who practised meditation as a means of coping with anxiety shared the belief that it helped them to confront pain, anger, fear, and blame in a constructive way.

Meditation permitted women to find a spiritual place within themselves that creates a comforting feeling that, 'all is well' and 'I am in control', quite often emerged from performing meditational rituals. Once women are able to view their illness in such a way, coping with a threatening illness becomes easier. Indeed, faith in the healing power of meditation can be a portal to the attainment of spiritual contentment.

People often talk of finding strength somewhere, somehow. In moments where our lives may be threatened, our inner spirit can tower above our fears and reassure us that life is worth living. Kahlil Gibran (1992:117-118) writes poignantly about the spiritual side to our existence,

You are not enclosed within your bodies, nor confined to the houses or fields. That which is you dwells above the mountain and roves within the wind. It is not a thing that crawls into the sun for warmth or digs holes into darkness for safety, But a thing free, a spirit that envelops the earth and moves in the ether.

Favourite pastimes and leisurely activities allowed women to focus on different thoughts instead of those related to cancer. Hobbies also helped to relieve stress and tension linked to living with an illness. Gardening, swimming, sewing, painting, walks, holidays, going out for coffee, visiting friends, returning to study, participating in a course to get a pilot's license, reading and listening to music, were some of the hobbies women in this study enjoyed participating in. Attending workshops about breast cancer, taking time out for oneself, facials and massages also brightened up women's days. Finally, those women, who adopted more of a selfish stance towards their time and energy, came to realise the importance of nourishing the soul. Only in loving themselves completely and without guilt, could women move on with strength, determination and courage.

Family and friends helped a significant number of women to come to terms with their illness. Being able to rely on a neighbour to take their children to school, having friends cook and clean for them helped women to feel they were not alone in their battle. Husbands, who were emotionally supportive towards their wives and listened emphatically to their cries, friends who were there to lift up a shattered spirit, daughters, who loved unconditionally, even if their mothers' breasts were deformed and mutilated, provided love and care when it was needed the most. Issues to do with body image and identity were better dealt with when women were treated with

compassion and notions of difference were annihilated. Further, carers, who witnessed the anguish and torment that accompanies breast cancer and were able to effectively communicate how they themselves were feeling, helped to shatter silence and uncertainties.

Young children were a source of strength for four of the mothers in the sample. Mothers with young children discussed the importance of surviving for the sake of their children. In this instance children provided a reason for mothers, scared of abandoning their children to live. There was not one mother who didn't speak of the need to fight breast cancer for the sake of her child or children. For those women who had younger children, the fear of leaving them motherless was inescapable. Mothers who had babies and toddlers were also concerned with what would become of their little ones if they were not around to protect and love them. Whilst they trusted in their husbands' abilities to look after their children, they believed their love was necessary for their child/children's emotional stability. Whenever mothers spoke of their fears of dying, their deep concerns were always pointed to whether or not their child/children would remember them if they died. Would their child/children be treated in an affectionate way by a stepmother should their husband remarry? Who would be there when their child/children needed their mother's touch, their mother's soothing voice and caresses? The tears seemed always to eventuate at this point, flowing uncontrollably, and their raw emotions were unveiled. But, amidst the uncertainty of a mother's future was a burning desire to live for the sake of their children.

Grandchildren also served to empower and encourage the recovery of two of the grandmothers interviewed; grandchildren were also a strong motivation to live for

grandmothers wanting to be there for their grandchildren during the various stages of their growth.

Less common themes linked to coping involved competent medical professionals. Practitioners and medical professionals were seen to play a major part in helping women cope with breast cancer. While not all practitioners were supportive, those who were assisted coping in a variety of ways. Firstly practitioners are responsible for treatments, medications, surgery, blood tests, chemotherapy and radiotherapy. Doctors, who spoke to their patients with empathy and respect, were trusted and revered. Specialists, who consulted their patients, asked for their opinions on medications and surgery, were seen to be understanding and approachable. The compassionate doctor who was aware of the suffering encountered by his/her patient and who paid particular attention to the physical, emotional and psychological needs of the cancer victim, almost always provided relief from suffering.

Social workers in hospitals, who made women aware of the various resources open to them once they were discharged, supplied women with knowledge to healing pathways. Nurses, who comforted women at night, when the terror and horror of their affliction took hold, offered women with comfort and reassurance. Further, the surgeon who was there at the waking moment of their patient, to tell her that the operation was a success, and all would be well, understood what it meant to be afraid and scared.

Less common coping mechanisms raised by women in their battle with breast cancer also involved animals and a change of diet. Fran and Lisa spoke of the importance of their dogs in their healing and recovery; having a dog around was also great company for them when they were feeling alone and isolated. A change of diet was

outlined by Grace who believed that her eating patterns contributed to her spiritual well-being. Becoming a vegetarian assisted in her ability to cope with negative emotions. The creation of positive energy within, through an absence of meat, assured Grace that she was in control of her personal sustenance and this facilitated a positive outlook to recovery.

## **Conclusion: Faith and Coping with Breast Cancer**

My research sheds light on the various coping mechanisms relied upon by the women in this study. This thesis has sought to understand how these women cope with breast cancer and to determine whether global faith plays an important role in their recovery from or management of their illness. Further, the role of social networks in facilitating coping, the place of body-image and identity in battling illness have been focal areas of concern. The narratives women presented have not only provided a window into all these themes, but have also allowed insight into the nature of illness, dying, disease and cancer. Central to how the women in this research view their illness in a optimistic way is their ability to be courageous in the face of cancer, a willingness to hope for the future when all seems lost and a driving need to move forward — Coping for these women has meant adapting to radical life changes and remaining positive when all else seems bleak.

Each of the women interviewed spoke of an altered state of existence as a result of their diagnosis with breast cancer. In spite of the destructive nature of many of the "taken for granted" assumptions associated with sickness and dying, body image and identity, faith and spirituality, each of these women took responsibility for her own healing. Personal awareness of their illness and a self-directed outlook to recovery led them to find their own 'wells' of spiritual nourishment and empowerment. Further, many interviewees stated that breast cancer need not be portrayed as the destroyer of life, or as the grim reaper. Rather, breast cancer can be viewed as promoting a challenging and remarkable journey of the mind, body and spirit. Each of the participants spoke of her experiences with cancer as a transition; a passage of time that pinpointed what was really important and precious in her life. Cancer, most

Importantly, provided these women with the opportunity to reassess their lives, to throw away destructive patterns of behaviour and thinking. What evolved from their reshuffling of priorities was a new lease on life and an appreciation of each day that was lived.

Coping takes a variety of styles — what works for one woman, may not necessarily work for others. For example, there were nuances in relation to Global faith and coping. The narratives of the women made clear how their experiences with faith and spirituality varied. In a world considered to be secularised (Lyon 1999) these women relied upon non-secular practices in coming to grips with their diseased bodies. Six women relied on a more traditional outlook to religion in their coping. These six women, alongside the remaining fourteen women also chose alternative methods in their attempts to function productively. Thus, the responses of interviewees suggest that coping with breast cancer is not only tied to church attendance and prayers, but also New Age beliefs and practices. This suggests that examinations of women's health and their use of faith and spirituality as a means of coping with illness needs to understand the power of non-secular approaches.

At the beginning of this thesis two questions were raised — how do women with breast cancer discover some meaning in what appears to many to be senseless suffering? And how do women maintain optimism, or a sense that all will be well amidst bodily decay and ruin? Based on the experiences of women outlined in chapter seven, it can be said that meaning is acquired through a number of ways including attending support groups, social networks, and global faith. The issues of body image and identity will be discussed in relation to social support and global faith.

### **Support Groups.**

Eleven women interviewed noted the importance of attending support groups in their battle with illness. It was here that they were able not only to speak of their pain, but also listen to the heroic stories of others. In hearing how other victims of cancer coped, these women spoke of the need to hear of others who too had suffered a similar fate. In witnessing positive outlooks to recovery, these women also felt they were able to dispel feelings of vulnerability and powerlessness. Being able to identify with other women who were in a similar situation meant that they were no longer isolated in their pain; feeling connected to members of a support group and belonging to a fellowship exposed these women to lifestyles made up of a future, goals, choices, achievements. Eleven women in this study were therefore provided with an added sense of empowerment in the way they chose to live and deal with the various contingencies in their lives through involvement in support groups.

The importance of Support groups in educating their members on a wide range of issues was also a major theme that was discussed in the narratives of eleven women interviewed. Eleven women in this study felt that support groups were essential in that they informed them about different types of treatment, palliative care and relaxation techniques. Coming to terms with destructive feelings attached to their illness was also addressed at support group meetings. Further, they felt that they were able to deal with feelings of guilt or shame when they were able to discuss these thoughts openly with other women facing the same issues.

Understanding that there were support group members, who commonly encountered similar problems, helped all of the women in this study to find meaning in their suffering. Victor Frankl's (1959) philosophy of finding meaning in suffering, outlined in

Chapter two, describes this process. I refer to a most profound speech Frankl gave to his comrades while in Auschwitz,

I spoke of the many opportunities of giving life a meaning. I told my comrades (who lay motionless although occasionally a sigh could be heard) that human life, under any circumstances, never ceases to have a meaning, and that this infinite meaning of life included suffering and dying, privation and death. I asked the poor creatures who listened to me attentively in the darkness of the hut to face up to the seriousness of our position. They must not lose hope but should keep their courage in the certainty that the hopelessness of our struggle did not detract from its dignity and its meaning. I said that someone looks down on each of us at different hours—a friend, a wife, somebody alive or dead, or a God— and he would not expect us to disappoint him. He would hope to find us suffering proudly—not miserably—knowing how to die. (p. 100)

Like the inmates at Auschwitz, realising that negative emotions could be successfully dealt with and that hope should never be cast aside enabled all of the women in this research to take control of their emotional states of being. Watching other women find optimism in their day to day suffering through regularly attending support group meetings encouraged many of these women to find meaning and hope during their illness.

### **Global Faith.**

The ability to find meaning and hope was related to the emergence of global hope in the stories of these women. Smith's (1962), views on faith, which are given some attention in chapter two, can also be related to how the women in this study coped with breast cancer. Smith writes of the importance of viewing life in a confident and joyful way — to trust and love the world is to have faith — to have faith is to experience a divine link with the greater universe and all that it encompasses (p.12). Twelve women in this study, who were able to view their existence and their social environment in such a way, were described as having a kind of global faith. It was this global faith that facilitated an ability to face the day ahead, despite the uncertainty of their diseased bodies. Even though many of the women spoke of a

fear that their cancer might some day return, it was a global faith, a confidence in their world that reassured them that all would be well.

The views of Julian of Norwich used earlier to develop the concept of global faith has shaped the way I think about the effects of a global faith in a person's life with the end result being a feeling or knowing that, 'All will be well and every kind of thing will be well' (1978:Chapter27: 225). Norwich, who writes about the need to depend upon God as a means of salvation from the depths of pain and suffering, is important when we examine the role of global faith as a means of coping with breast cancer. Many women in this study did encounter the feeling that Julian of Norwich writes about. Thirteen of the participants spoke of a divine presence in their lives when dealing with illness. It was this inner knowing of the sacred within that helped them survive the emotional turmoil they were forced to endure — When the cards were stacked against them, when their bodies failed to function in a healthy and productive way, it was often a belief in the unknown, or a holy presence, or a spiritual being that provided them with relief from suffering. Joy and happiness, in the form of a divine presence, could still be grasped onto when all else failed. Whether it was meditation, or American Indians, or becoming a Vegetarian, or reading about Out of Body Experiences, somehow a link with a comforting and loving being was established. What resulted was an outlook to recovery that was good and healing and all encompassing.

Thirteen women that were interviewed spoke of closeness to God, or a strengthening of faith with the onset of cancer. Lighting a candle, or going to church, or meditating, was a passage, a road to reassurance. For these women, when facing the journey of illness with a kindred spirit, at the end of the storm, a rainbow soon surfaced. With this rainbow comes a pot of gold that is not tied to materialism, or social acceptance,

or even a healthy body. This pot of riches doesn't promise a life free of illness, or an absence of pain or suffering. What it does promise though is a way of functioning for women whose lives have been ripped apart by disease; this pot of gold represents control, trust and confidence when there is a connection with the sacred and divine. Julian of Norwich's (1978:Chapter 77:329) belief that, 'We are liable through our feebleness and folly to fall, and we are able through the mercy and grace of the Holy Spirit to rise to greater joy', epitomises the importance of reliance upon a greater force as a means to overcome all that is fearful and tragic in our lives.

### **Social Networks.**

Participants in this study also spoke of the importance of social networks in their lives. Family and friends, work colleagues and medical practitioners assisted their ability to cope with illness. All the women interviewed reported that it was important to have someone they could depend upon for emotional and physical support. Having a sister clean their house, or being able to rely upon a neighbour to cook and run errands, assisted interviewees in their day-to-day lives. Further, medical professionals who provided a high standard of care, who treated their patients with respect and kindness, helped three women examined in this research to feel confident about the management of their illness. Meanings thus emerged from their interactions with those people they interacted with. Realising the true importance of family and understanding the need for a close network of friends, helped to establish deeper and valuable connections with loved ones.

Supportive husbands or partners, who accepted surgically scarred breasts, also helped three women in this study to manage issues linked to body image and identity. These women's views of their body image were also outlined in some of the stories. I expected to find more reference to shattered perceptions of self as a result

of breast cancer, yet seventeen of the women interviewed accepted their altered body. Acceptance was attained through a variety of means such as breast implants, supportive partners and a belief that the loss of a breast was the price paid for survival and ultimate happiness. As Rachel (L: 1592-1596) asserts, 'they could inflict whatever drugs they wanted into my body as long as I am around for my kids. I can live without a boob and I can live without looking sexy at the pool. I have the love of my kids and my husband and my family and that's all that matters'.

### **Body Image.**

The concept of body image was discussed in chapter three because of its direct relevance to the experience and meaning of breast cancer. Themes such as self-acceptance, confidence, self-worth and notions of attractiveness, which are tied to the shape, size and form of a woman's body, are given careful consideration (Fallon 1990). Often, how powerful a woman feels is reflective of how she perceives her desirability and the way she sees herself sexually (Zimmerman 1998). Breast cancer can therefore wreak havoc on a woman's sense of satisfaction with her body — a deflated sexual ego, often the result of a mastectomy, can lead to distress and shame (Armistead 2000). Sontag (1978) writes about the way in which cancer is viewed socially and culturally as 'ill-omened, abominable and repugnant to the senses' (p.9).

Given the narratives examined, negative literature on body image and breast cancer is not applicable to all women. Seventeen of the women in this study who had lived through the experience of breast cancer did not see cancer in such a way. Instead these women spoke of breast cancer as positive, promoting changes in their lives that led to greater fulfillment and personal satisfaction within. While three women such as Kay discussed a disgust of her breast and body following surgery, others

saw their cancer in an optimistic light. One example is Grace who came to view the absence of a breast in a loving and spiritual way. Grace in fact used the word 'Beautiful' and 'Happiness' numerous times when discussing her cancer experience and spoke about showing greater affection for the breast that was gone (L: 2060-2066). Many of the narratives outlined an ability for some women to look upon illness in an constructive way; cultural expectations and notions of beauty were shattered when these women came to see their life and their existence as being more important than their physical appearance.

### **Identity.**

Identity is another major theme raised in chapter four of this thesis where I argued that a woman's sense of identity is tied to a feeling of belonging and acceptance within her social world. Identity, then, is a way a person sees his or her self in the scheme of things and is heavily influenced by social factors that shape and manipulate human lives (Woodward 1997). It was also noted at the beginning that when illness strikes a person's identity can be severely shattered. Herzlich and Pierret (1984:54-55) note,

To be sick, then, more and more frequently means to live with an illness or a handicap. This illness tends to become an identity for the sufferer, and a category of social perception for the others...Henceforth illness is signified by time off work, a medical diagnosis, the taking of medications that punctuates the day...The sick or the handicapped person is afraid of being stigmatised and of being pitied.

An individual's identity is anchored around social constructions such as body image, sexuality, social roles, health and illness. When faced with sickness and an unhealthy body, there can emerge an identity crisis (Reker and Wong 1988). Dread and fear can soon replace confidence and certainty within when a body is plagued with a disease that transforms healthy bodily cells into death traps. In the case of breast cancer, women diagnosed with this illness can experience a sense of isolation and

rejection. The victim of breast cancer for example, who is the mother, the lover, the sister and the friend, can find herself questioning all that she is, the social roles she has acquired and those expectations placed upon her when her life is at risk (Corbin 1988).

At the end of chapter five a question was posed in relation to the connection between identity and global faith. This question sought to clarify the role of global faith in providing stability to those women whose identities had become shattered and bruised. Since not all the women interviewed expressed a type of global faith my consideration here focuses on the stories of those women where global faith was indeed apparent. For twelve women, global faith not only assisted their ability to cope with illness, but also empowered them to view their social world in a different way. For these women, with the presence of global faith came a need to change certain elements in their lives. Global faith provided them with a feeling that their lives could be lived in a positive and optimistic way even if cultural and societal forces told them otherwise. A belief in a sacred and divine force helped these women to rise above negative labels that are often linked to being sick.

Some of the women interviewed no longer wanted to be labelled as 'the sick person', 'the cancer victim', or 'the terminal patient'. Inner peace and acceptance, attained through their religious beliefs, helped them to take control of their lives. In being recognised for who they were as individuals, rather than the social role that had been placed upon them, these women could put an end to inauthentic lives. Simply being able to focus on their own needs, as opposed to the needs of others, meant that difficult decisions were made to eliminate feelings of inadequacy and defeat. Old friendships were dissolved and new friendships established; marriages and relationships were re-formulated involving the introduction of a different set of

expectations and needs; mothers began to view themselves as more than the sum of their children, seeking to become more selfish with their time and energy. What resulted in all these changes was an attitude to life and newfound identities that placed at its centre women's concerns, women's views and women's power. Such an identity sought to influence the course of events that would dominate these women's lives.

Identity is shaped and strengthened by global faith, which can in turn precipitate an ability to cope with illness. Making personal changes in life created exciting possibilities and opportunities. Women spoke of newfound interests that would not have otherwise been present had there not been the incidence of cancer in their lives. Placing a child in care allowed one mother to find the time to go out for a coffee, swim a few laps at the local leisure centre and spend quality time on her own. A businesswoman spoke of hiring a personal trainer to help her with dietary and fitness concerns stating that, for the first time in her life, she had been selfish in her choices. Going for walks on the beach, joining a sewing club, becoming a member of the Australian Women's Pilot Association, were just a few activities that inspired and motivated women in their dealings with breast cancer. Finding meaning in their lives was thus achieved through choosing to spend their time in their own way; finding meaning in suffering was achieved when women realised the importance of doing things for themselves because they were worth their own attention and care.

There are several responses to the second question raised in chapter two, how do women maintain optimism, or a sense that all will be well amidst bodily decay and ruin? Women's narratives indicated that core optimism in the world and surrounding environment was achievable when there was a connection with the transcendent. Nine women spoke of feeling a sense of God in their lives and it was this belief that

provided them with a feeling of hope and peacefulness. Three women believed that they were being watched over by a divine being — guardian angels, spirit guides, and dead relatives were outlined as being important in establishing a connection with a sacred force. Those women, who trusted and relied upon a divine force as a means of coping with cancer felt guided in their battle; women who had global faith felt safe in their world even if their future was uncertain. Global faith thus facilitated a kindred spirit whereby women could develop a certain attitude that would allow them to find personal satisfaction in their lives. Believing that there would be a higher presence to guide them at the moment of death, trusting that a sacred being had their best interests at heart, helped to ease the fear of dying. In being granted an extra hour, an extra week, or an extra year by a transcendent force, some women encountered a sense of appreciation of life, an appreciation that many women did not have prior to their diagnosis.

The theme of re-enchantment was evident in many of the stories presented. Seven women took delight in the simple pleasures of life and found comfort in nature. Watching magpies walking on a front lawn, spending time in a garden with colourful flowers, taking in the splendour of natural waterfalls and historic landmarks, contributed to a certain re-enchantment of life and life forms. The re-enchantment of their lives meant the awakening of a scared spirit; a spirit that had been downtrodden and silenced by the fear of bodily decay and the terror of dying. The emergence of a connection with the world assisted in women's abilities to cultivate an enchanted soul. As Moore (1996:ix) so beautifully writes,

Enchantment is a spell that comes over us, an aura of fantasy and emotion that can settle on the heart and either disturb it or send it into rapture or reverie...An enchanted life has many moments when the heart is over-whelmed by beauty and the imagination is electrified by some haunting quality in the world or by a spirit or voice speaking from deep within a thing, a place, or a person. Enchantment may be a state of rapture and ecstasy in which the soul comes to the foreground, and the literal concerns of survival and daily preoccupation at least momentarily fade into the background.

Overall, re-enchantment can be traced to sixteen women in this study. Re-enchantment involved taking on board a certain kind of religious, spiritual or enchanted orientation to their lives. Simple activities such as going to church and praying, or meditating, or going for nature walks, provided a tremendous amount of spiritual comfort that could not otherwise be attained through scientific modes of healing. Finding one's own space, where thoughts could be addressed in a positive way facilitated coping. When these women were responsible for their own healing, when these women established their own notions of the sacred and divine, inner contentment and harmony was achieved.

### **Conclusion.**

This thesis has described the role of global faith, alongside such other factors as support groups, social networks, in the way twenty Australian women have coped with their breast cancer. The role of the spiritual and the place of faith in the lives of some of these women is clear. Further research into coping with cancer would do well to pay attention to these factors as well as the more usual physical and psychological ones.

## Appendices

Appendices for Chapter Four.

**Appendix 4.1. Print of Vermeer's 'The Lace Maker' 1969-70**



## Appendices for Chapter Six

### Appendix 6.1: Layout of the Questionnaire

#### COVER LETTER:

My name is Marcelle Cacciattolo and I am currently completing a P.H.D at Monash University (Clayton campus). My study is focused in the area of dying and faith. More specifically I wish to investigate what role faith plays in helping women with advanced breast cancer to accept, cope and re-evaluate their illness. It is hoped that this research will allow greater understanding of the role of faith in allowing women to accept dying in a positive way.

As part of my study I am administering a list of questions which asks you to tell your story. More specifically these questions ask that you detail your experiences with cancer. Your responses will enable me to understand the extent to which cancer has affected your life and your means of coping.

I will also be conducting interviews in relation to the area under investigation. Results obtained from your transcripts remain strictly confidential and real names will not be used in the thesis. Details obtained relating to places, events and people will also be altered to protect those involved.

At the end of the list of questions you have been given, there is a section which invites you to be interviewed should you wish to participate further in the study. In depth interviews will be carried in an attempt to investigate your views in more detail. Questions asked in the interview will be a follow up of those you have answered in the handout provided. A more depth analysis of your responses will hopefully be attained through the interview. Clarification of your responses may also be followed up through the interview process. Again, confidentiality will be respected and is of major concern in this study. Consequently, pseudonyms will be used to protect your anonymity.

Interviews will be carried out in either your house, or a comfortable setting decided upon by the both of us. Interviews will last for approximately one hour and will be taped providing you agree to this. Follow up interviews may also occur should you wish to continue with the study.

Finally my supervisor is Professor Gary Bouma. He is the deputy head of the department of Sociology and Anthropology and should be contacted if you have any uncertainties relating to my study. He may be contacted on 99052982. I may be contacted on 99052999 should there be any questions relating to the study being undertaken. My postal address is as follows:

Monash University (Clayton campus)  
Department of Anthropology and Sociology  
Clayton, Victoria, 3168.

The address for the standing committee on ethics in research on humans is as follows should you need to contact this organisation:

Standing Committee on Ethics in Research on Humans (SCERH)  
Research Grants and Ethics Branch  
Monash University  
Wellington Road  
Clayton Vic 3168.

Thank-you for your co-operation.  
Yours faithfully  
Marcelle Cacciattolo.

Monash University  
Department of Anthropology and Sociology

Title of Project: Coping with Breast Cancer: Women's Lived Experiences with Illness and Dying and the Role of Faith in Facilitating Well-Being.

Project Number: 99/053

This handout is an attempt to gain first hand knowledge on the impact of breast cancer on your life. Those questions that you will be asked endeavour to elicit your personal story. Your responses will enable me to gain an insight into how breast cancer has touched your life. Further, your responses will allow me to gain an insight into those sources of support that have played a part in your day to day living. Confidentiality will be respected and real names will not be used. Names of events and places will also be altered to protect your anonymity.

There are no right or wrong answers to the questions listed below. Your responses to these questions will be valued and respected. Your thoughts and experiences will also be kept confidential. Should you require more paper for writing there are extra sheets at the end of the handout. Thank-you for your time and for giving me the privilege to read about your journey with breast cancer.

[illegible]



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2. (a) If you haven't already said what major events have taken place in your life since first being diagnosed with cancer, can you please list and describe them here.

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(b) Have you resolved certain aspects in your life that up till now had not been resolved? Please describe them and how they were resolved.

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3. What do you do during times when you feel threatened or in pain?

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[illegible]

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6. Are there any issues that you are struggling to deal with? What are these issues and what help is available for you to make sense of, or come to terms with such issues?

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7. Tell me how it is when you reflect on your illness. What emotions come to mind and is there a source that allows you to view your illness in a positive way?

[illegible]

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9. Is there a source, or sources in your life that has enabled you to deal with your illness in a positive way? Please give a detailed explanation when answering this question.

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10. Please tell me your faith journey, or your spiritual life.

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### **Background details**

Age: \_\_\_\_\_

Occupation: \_\_\_\_\_

Post code: \_\_\_\_\_

Religion\_\_\_\_\_

Thank-you for taking the time to share your experiences with breast cancer. Should you have any complaint concerning the manner in which the research (Project

99/053)) is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary  
The Standing Committee on Ethics in Research on Humans  
Monash University  
Wellington Road  
Clayton Victoria, 3168  
Telephone (03) 9905 2052 Fax (03) 9905 1420

I am interested in conducting interviews with women like you who have breast cancer. If you would like to be interviewed to discuss in greater detail your responses to these questions, please fill in the following:

Name:

Postal Address:

Contact number:

If you would like a summary of my findings please put your name and address here and I will send it to you.

Name and Address: -----  
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## Appendices for Chapter Seven.

### Appendix 7.1. Women's Stories.

1 *Fran*

2 F: Six and a half years ago I was diagnosed with breast cancer. In the beginning I  
3 was in shock and it lasted months. I was fine in hospital. All the visitors came in and  
4 with all the flowers and all the attention of the world around you, you didn't have time  
5 to come to grips with cancer. This was because it was probably the last thing in the  
6 world that I thought would ever happen to me and that's the problem with illness you  
7 never think it is going to happen to you.

8  
9 I have always been the nurturer and the mother figure. I honestly think I didn't come  
10 to grips with it possibly happening to me. So I remember being in the house alone  
11 about four months out of hospital and I broke down and I cried and I cried and I felt  
12 so desolate and so alone and I thought what am I going to do? I didn't know what I  
13 was going to do? And at that stage this is going back six and a half years ago there  
14 weren't any breast cancer support groups. There were general ones and I didn't feel  
15 well and didn't want to go out. So there was no support, nothing at all except my  
16 family who were magnificent. Yet, sometimes when you're the victim you don't want  
17 to worry them with absolutely everything so I would watch what I said to them. In the  
18 process I felt very very alone. I remember that very clearly and I had the feeling that  
19 absolutely no one understood the extreme trauma I was going through. Anyway time  
20 went by and one day I had the radio on. A woman was being interviewed and she  
21 was setting up a breast cancer support group at a clinic where she worked. That was  
22 my first support out in the arena and it was terrific. The only criticism is I was fourth  
23 stage and some of the other girls were first, second or third stage. Maybe the feeling  
24 I had is that I couldn't really express myself because it was a bit scary for them to  
25 think, "Oh this is what it gets to". I would hold back from saying too much and that  
26 didn't quite help me. Anyway then a researcher for breast cancer approached me.  
27 They wanted me to do questionnaires for two years and I agreed to that. Then they  
28 asked if I wanted to be apart of the research group. It was to be based on a model  
29 adopted in America that support groups can actually lengthen your life as well as the  
30 quality of your life. Anyway I agreed and that was the best thing that happened to me  
31 because we don't have to protect anybody because we are in all in the same boat  
32 and we have become a very close unit; we are all good friends. There are social  
33 activities outside our support group. We ring each other up and it really is a  
34 worthwhile experience. I wouldn't be as good as I am now without it that's for sure.  
35 So I think you need support from your family which is really most important, but then  
36 you also need to be able to express yourself outside the family.

37  
38 M: *Were there any major events that took place in your life since being diagnosed*  
39 *with breast cancer?*

40  
41 F: Maybe only coming to grips with the difference between my husband and myself. I  
42 think that highlighted the type of person he is against the type of person I am. I would  
43 say he is an inward thinker and deals with all his emotions within. He doesn't express  
44 his problems at all. And I think it does show up in a family the strength and the

45 weaknesses and sometimes you can't pick who will, or won't be there for you. I found  
46 it very much amongst my friends. My very best friend at the time was quite silly about  
47 it all. She had me dead and dying and in the box. She would say outrageous things  
48 like you have only got a year to live and what are we going to do without you? I had  
49 to come to grips with that and that was hard. Eventually I had to say she is the silly  
50 one, she has the problem but I don't have to listen to her. And actually it sometimes  
51 works in your favour because you get so determined to not let them be correct that it  
52 gives you a bit of fight. They moved down to the Peninsula and the distance saved  
53 the day. We are not as close and she cannot control my life like she used to.

54  
55 *M: In what ways has having cancer changed your attitude to certain things?*

56  
57 F: I would honestly say that my journey with breast cancer has forced me to change  
58 considerably. Now I am not always available to some people. I now have my chosen  
59 friends who are fantastic. I don't have many but there are two who are great friends.  
60 My best friend who wasn't so supportive used to monopolise me and my friendships  
61 with others couldn't grow. Now things have changed. I have a close friend now and  
62 we are both interested in art. We go to an art gallery and have lunch once a week,  
63 which is a good thing because it gets me outside myself. Another thing is that cancer  
64 has changed my perceptions about dying. When I began attending the support  
65 group, I had a huge fear of dying, or the way I might die. Some women didn't die well,  
66 they chose to not accept it. The majority did it well. There was one girl who was  
67 important to us. Her name was Jamie. She was about thirty-eight had three young  
68 children. It was very touching to see how she dealt with her illness. To see that girl  
69 record her family on a video recorder and write them letters made us all realise how  
70 courageous she really was. Another thing is that I have had to go to about eleven  
71 funerals. That has been hard and in another funny way it makes you face things like  
72 life is not forever and if you keep pushing things under the carpet well I have a saying  
73 it always comes around and bites you on the bum. I think this has made me face up  
74 to cancer and I think I have dealt with it quite well.

75  
76 *M: Are there any other major events that took place?*

77  
78 F: Well my old dog became sick and we had to put him down and that was so  
79 traumatic. Eventually I got another dog, my precious dog Johnny. My husband and I  
80 adore him and he adores us. I am absolutely sure he helped me with my coping. The  
81 love they give can mean so much at times. My husband noticed the dog adored me  
82 from the first minute; it was like a coming together. He is such an affectionate little  
83 thing who has given my husband and I enormous pleasure. Another thing that has  
84 helped me is that I have always painted but always in a slap dash fashion. I have  
85 been doing it probably since I was eighteen years of age but never really got into it. I  
86 was always too busy. But, when I had to give up work because of my treatment, I had  
87 a big void in my life. I remember one day saying to myself, "What am I going to do?" I  
88 decided that I would start painting again. It allows me to express emotions about  
89 cancer. Initially I went to classes again and I totally lost myself for the two hours I was  
90 there. When you have cancer you can't help it. Cancer is always there at the back of  
91 your mind and it is nice to have relief from it.

92  
93 *M: Are there any other sources of support that you depend upon to cope with breast*  
94 *cancer?*

95  
96 F: My friends, the support group, the animals and my painting. But I also love going  
97 out to dinner, theatre, and films. I am more appreciative of the moment now, whereas  
98 before I would have probably been very busy. I was a very busy person who tried to

99 fit a lot into the day. Now I know I can just relax and stop and smell the roses.  
100 Another important thing to me is my garden. This has been a growing thing and I like  
101 design so I like thinking about the design of a garden. With all these recurrences I am  
102 not able to get out there and work like I used to so that is a bit of a downer.

103  
104 *M: Tell me about your body image and sexuality.*

105  
106 F: I don't think it is as big an issue as those young girls who are between the ages of  
107 thirty and forty. I was fifty-four when I was diagnosed so it wasn't as devastating. My  
108 husband was supportive so that helped. I have heard of girls whose husbands turn  
109 away when they are getting undressed. But with all the treatment I have had there is  
110 not too much sexuality. I have lost my hair twice and the first time was pretty  
111 devastating because I had very curly hair and it was considered probably my best  
112 feature. To see it fall down the plug hole when I shampooed it was devastating. But I  
113 said to myself it is only hair and it will grow back. You just have to say to yourself if  
114 you want to live you have to put up with this. I mean I would rather live and have no  
115 hair. Looking at people who have it tougher than you would help. Giving up work  
116 effected me quite a lot. The loss of interaction with people effected me. After the  
117 initial fuss and bother when everyone comes to visit you, you are like a celebrity.  
118 That does die down and then it gets quite lonely. That is when you need support.  
119 There was no interaction with the community, which I used to like. I am not the type  
120 who will ring anyone up when I am miserable, I never do that. Yes the group has  
121 been a very positive experience in this sense as I can ring people up from the  
122 support group when I feel down.

123  
124 *M: Are there any issues you are struggling to deal with now?*

125  
126 F: I look at dying in a different way. It used to be absolute fear because I have seen  
127 my mum die due to a heart issue and it affected me enormously. When my half  
128 brother died that was very distressing as well. And I thought that was how everyone  
129 went. But since I have belonged to the support group and had to deal with women in  
130 the same boat as me I have come to realise it isn't necessarily all that bad. What I  
131 have realised is that this is a time when you can really get your relationships together  
132 with your family and friends, put things in order, no regrets. We have got time to do it  
133 and I am more aware of the support you get from hospitals in terms of palliative care.  
134 That makes me feel safe as well. I am not very spiritual. I love life, I love animals and  
135 nature. Good friends and family are so important and that is where I get my  
136 spirituality. My belief is that God is goodness and there is goodness in people.

137  
138 **Kerry**

139 *M: Please tell me about how you came to find out about your breast cancer and how*  
140 *you felt at the time.*

141  
142 K: Basically I knew that I was sick even though I didn't know I had breast cancer. I  
143 was very fit and used to go out riding and swimming before I went out to work. I  
144 started to get very sick and I would have to get off my bike and I would nearly pass  
145 out. There were a few other funny things going on so I went to the doctors and told  
146 him what was happening. He decided I should see a psychologist. I knew him  
147 because I was a medical representative and I saw him for work. I told him, "Your  
148 trying to say I have anxiety. I am telling you that I don't have anxiety because I don't  
149 have anything to be anxious about. I am house hunting to buy something, but that  
150 doesn't send you off the edge. You are not listening to me. There are things going  
151 wrong with my body. I know my body". The doctor kept on insisting that I see a  
152 psychologist. Eventually I got so fed up with him that I went to leave. He put his foot

153 against the door and slammed it shut. He then started saying, "I really think you need  
154 to see a psychologist!" That was terrible. Even if he thought someone had a  
155 psychological problem you don't approach people like that. So I left his office and  
156 didn't worry about what he had said and the way he approached me. Nearly a month  
157 later I got out of the shower and I noticed that my nipple looked funny. When I  
158 touched it there was a lump there. I went to the doctors and they said that I needed  
159 to get an ultra sound and mammogram done. The doctor said, "Don't worry about it".  
160 The doctor didn't think it was anything serious. I told him, "In my medical opinion you  
161 don't just get a lump like that for no reason. I think I should have a biopsy".

162  
163 *M: How is it that you know of all the terms?*  
164

165 K: I am a nurse and I think that saved my life because I knew not to take any notice  
166 of what some medical professionals say. Nurses know that you don't just take  
167 everything as gospel. If things aren't right you have to take charge. I asked the doctor  
168 for a referral and they found I had breast cancer. I was so shocked. Breast cancer  
169 was the last thing on my mind even though I knew I wasn't feeling right. I did a lot of  
170 research to find out who would operate on me. I decided to go with this private  
171 surgeon because the public one was pretty horrible.

172  
173 My first meeting with the surgeon was weird. The surgeon was really upset telling  
174 me that I had breast cancer. I was in my nice business suit and I think it upset him  
175 that I was young and had so much going for me. I was thirty-four and he had tears in  
176 his eyes. He wanted to ring my parents and I told him that I would rather ring them  
177 myself, after all it was my problem and they were my parents. I knew that I needed to  
178 control the situation from the start. I actually went home and he finally let me escape.  
179 He said, "You have a boyfriend don't you, you live with someone don't you?"

180 "No I live on my own" I replied.

181 "But you have family?"

182 "No I haven't. Look it will be o.k.", I said.

183 "I just think someone needs to hold you even tonight", he told me. He was so  
184 concerned.

185  
186 So I got home and I thought I would ring this guy that I had sort of being seeing over  
187 a period of about ten months, but we weren't serious. So I rang him and he virtually  
188 didn't want to know about me. While I was on the phone to him another call was  
189 coming through so I said I have to go. The other call was the surgeon making sure I  
190 was o.k. and I thought what a contrast. Anyway I rang my parents and did all that. It  
191 was really hard to try to tell people because you didn't want to upset them. I rang  
192 some of my really close friends. I had a really close friend I couldn't tell. I had to get  
193 someone else to tell her and I did that with a couple of people. I thought it would be  
194 better that they react to someone else. I wanted them to have that time to get upset  
195 with someone else rather than not showing me any emotion for fear of my reaction.

196  
197 I rang another girlfriend and she came over with the girlfriend I couldn't tell. So they  
198 took me back to her place and we drank copious amounts of alcohol and we ended  
199 up by laughing. By that stage I had been told I had to have a mastectomy so there  
200 were even a few jokes said about that. I stayed with those friends for six weeks. I had  
201 the operation. When I was lying in hospital I don't know why but this little thing said to  
202 me you can sink or you can swim. But, this voice said if you sink now it is going to be  
203 a lot harder to fight back. I thought I am going to start swimming now. I have had to  
204 confront some incredible things in my life. I have made it through them and I thought  
205 that some good will come out of this. This need to find something positive through  
206 something bad is really important to me. From there I did radiotherapy and went back

207 to work. I didn't even worry about my scar. I heal really nicely and I am so pleased  
208 with it because I really worked with putting vitamin e cream on it.

209  
210 Then my surgeon started pushing me to get a reconstruction. I told him that I don't  
211 care what I looked like as long as I was all right. I made an appointment with a plastic  
212 surgeon and he told me such horrific things about complications that can arise from  
213 the surgery. So I walked out into my car and my surgeon rang me and he said, "What  
214 are you doing?" He sort of took on this fatherly role and his nurse did too. I didn't  
215 think the whole thing was all that bad. I had beautiful friends. I was so lucky. I used to  
216 go and have lunch with them a lot. Eventually I booked in for the operation and I had  
217 put on a stone and a half. I had the operation and it was horrific.

218  
219 *M: Body image. You said, "I don't really care", but how did you feel when you had the*  
220 *mastectomy?*

221  
222 K: Sometimes I sort of think I didn't even say good-bye to it because it had cancer  
223 and it had to go. My body image was fine. I got this prosthesis. I didn't even go out  
224 and get a proper one I just got one and said that looks about right. I used to just wear  
225 that. I remember I was at this elite golfing tournament. One of the big golfers wanted  
226 me to dance with him. Well I had this prosthesis sitting there with a low top and I was  
227 jumping around and I thought well if it comes out it comes out, but it never did and it  
228 just didn't worry me. I thought it was so funny. It is your attitude and if you're not  
229 conscious about it, no one else will be.

230  
231 *M: Were there any positive sources that help you to come to terms with your illness?*  
232

233 K: One thought that always went through my mind was what if I die? You have all this  
234 support on earth and they can all be there but if you die where do you go? It is a  
235 journey you must really face alone. Because of that I think it made me stand up and  
236 be accountable for myself. Whatever my attitude was towards the whole thing was  
237 going to reflect on me. The way you are towards other people and what you reflect  
238 you get back as well. I went back to work and started radiotherapy. I was working all-  
239 day and getting radiotherapy. My days were very busy. Towards the end I couldn't  
240 even drive so everyone was driving me to the hospital when I needed treatment.  
241 After radiotherapy finished I got tired and quite ill. I got chronic nausea. I was  
242 diagnosed in the April and by the November I rode my bike and I collapsed. I couldn't  
243 even get off the ground. I couldn't even sit up and it was embarrassing and there was  
244 a magpie swooping me. After that I struggled to go to work and in the end I couldn't  
245 do it. I didn't have a supportive boss and she kept pushing me. In the end I went off  
246 work and I thought I would have to resign. That was really emotional. Just the fact  
247 that I was trying to come to grips with my illness and my boss was making it difficult  
248 for me. While I was off I had that reconstruction and I am happy.

249  
250 *M: What things do you like to do that make you feel better?*  
251

252 K: Support groups make me feel good. I was one of the instigators starting up a  
253 support group for young women. It is only once a month, but it is very much a social  
254 gathering thing and more a positive thing. I think it is good to be around people who  
255 are your age. They really know what you have been through and these young women  
256 know what you are thinking and where you are coming from. Even if you go along  
257 and you don't even talk about what has happened to you, you know that there is that  
258 understanding there. Because no-one else wants to know about your worries.  
259 Another thing that has helped me is I learnt to meditate. A girlfriend brought me a  
260 book. I was such a hyperactive person back then that I thought meditation was

impossible to do. The first time I went along to meditation classes I just sat there. I was horrified at how I was going to keep still for ten minutes. But in the end it worked and I couldn't believe it. I did a lot of it. You can have a lot of things on your mind. They might be things you can't control all the time. Yet, meditation gives you that peace of mind you're searching for. I also run. A run feels so good and I meditate when I run. Being physically active has helped me enormously. It took a long time to get my fitness back. At Christmas I went on my bike and rode without being sick. I thought all my Christmases had come at once.

*M: Have there been any major life events that have occurred as a result of breast cancer?*

K: You slowly realise all these things when you have breast cancer. When I was off work I thought I have to change my life in some ways. I think I decided that I needed to feel peaceful so I really worked on that. There were family issues that I realised had completely stressed me out and I worked through all of that. I confronted them and dealt with them. I am more selfish with myself. I had previously put everyone else before me. I don't do that now. Another thing that has changed is my attitude to work. If I am feeling tired at work, I will take a day off. I wish I did that before. It is so important. Having cancer has made me think about my own needs and I am responsible for looking after my well-being.

*M: Tell me about how it is when you wake up in the morning? Is there something that gives you a sense of hope?*

K: I very much realise that every day is a different day. I try not to look at the whole picture and to take each day as it comes. One of the big things when I had cancer was that I made sure I looked nice each day. I made sure that my hair was nice. I do that anyway but this time I knew that if I looked all right then I would feel all right. If I got up and looked in the mirror and saw I was in an exhausted state it would frighten me. So that was a big thing for me. Looking nice and fresh and happy and that was how I wanted to commence each day.

*M: When you reflect back on your illness what emotions come to mind?*

K: Sometimes I think "wow" how did I get through that? The way I got through it was to take each day as it comes. Some people say I got this for a reason. I don't believe that. I think it is not right that someone has made me have this for some reason and I have to work out what it is. I don't think like that. I think this has happened what can I learn from it. Rather than it being a punishment I look at it as something that happened and that I need to draw meaning from. I remember I used to go to this alternative cancer group and they would say you caused it. I had a problem with that. I thought I am not taking that on board, I am not going to put myself through that. I know that I did have stress, never stood up for myself, but I don't believe you should see cancer as being your fault.

*M: How has your medical background helped you with your illness?*

K: I want to make people aware that they have to be accountable for their own bodies. Women shouldn't just rely on their doctors for advice. I decided we should have a young women's cancer awareness day. This would make women realise how many of us are out there and that we are all survivors.

*M: Has cancer brought about some kind of faith journey for you?*

315 K: I think I am a spiritual person. I had a bit of an interest in spirituality before cancer.  
316 I do love people who are so inspirational. I am in the Australian women's pilot  
317 association and they are the most incredible people you can meet. A friend of mind is  
318 in a wheel chair and she flies. The things she has had to endeavour in her life have  
319 been incredible. And everyone influences every one in different ways. I really like to  
320 read inspirational books and I love being around people who are amazing in what  
321 they have done and what they believe they can achieve. I was brought up a Catholic  
322 and I have never met such a lot of hypocritical people in all my life. People always  
323 bagging people and bitching. Look when I got sick I never prayed. I am just not a  
324 religious person. I just want to be the best person I can for me and for the people I  
325 love and for those who come my way. When you start thinking about death and you  
326 realise how lonely it would be to die and have no one holding your hand, you become  
327 frightened. Even though I thought this I didn't feel the need to turn to a religion to  
328 ease my pain.  
329

330  
331 *M: Is there anything else you wanted to raise?*  
332

333 K: I was misdiagnosed with cancer and in the end it was left up to me to suggest  
334 getting a biopsy. Ever since then I have had this bug in me. If I could try to save at  
335 least one life by making somebody accountable for themselves, I would be happy. In  
336 starting up the young women's support group I feel that I have really achieved  
337 something. When I was firstly diagnosed, I kept on going to groups where there were  
338 older women. I kept saying to them "Your needs are so different to mine". The  
339 women didn't feel this was true. One night I said goodbye to all of them. As I was  
340 walking out the door I thought to myself most of those women are going home to their  
341 families, their children, their husbands. I don't have that. I am going home to a house  
342 on my own. I thought that was interesting.  
343

344 **Sarah**

345 S: When I was diagnosed with breast cancer a great support was a cancer therapist.  
346 During that time a cancer seminar had taken a place up in some convent and it was  
347 starting up this alternative way of coping with breast cancer. I think you went once a  
348 week for twelve weeks and there were all different cancers, not just breast cancer.  
349 You learnt about food and meditation and other alternative things, which I felt, were  
350 really important. Another thing was that I didn't like the medical professionals taking  
351 control over my healing process. It was therefore important to find alternative help.  
352 This is where this therapist comes in. I would use his books like Bibles. I underlined  
353 them and got so much out of reading them in hospital. In my ward there were a lot of  
354 women who had breast cancer and were out of control. They were often crying and  
355 hysterical and very worried and upset. Unlike these women, I found the fact that I  
356 was trying to heal myself very cathartic. I listened to Enya on my tapes and read  
357 these books and felt ok about my situation. On the other hand I was very against  
358 having radiotherapy. I had radiotherapy for five weeks. I rang my specialist on the  
359 phone and told him that I would not have radiotherapy. He told me that I would die.  
360

361 *M: There is this dilemma where there is the scientific approach verses a holistic*  
362 *approach to healing.*  
363

364 S: Over the last ten years I have been diagnosed twice with cancer. I have met two  
365 women who had been diagnosed like me and had absolutely given the medicos up.  
366 One went to live in the bush and both have given up their jobs and done amazing  
367 alternative things. They have actually healed themselves. I have heard a lot about  
368 shrinking cancers with self-healing and the right diet, the right approach. But of

course when you're in that situation it is quite scary to say bugger off medicos. These two women were obviously stronger than me in that respect. You get all this shit thrown in your face like, "Oh my God where is all your responsibility to your children and your family?"

*M: Who do you get that from?*

S: From people like my mother who said, "You should have had your breast removed from the beginning. If you had of you wouldn't have had the two other cancers". It's like it is a responsibility for you to keep yourself alive for other people.

*M: How do you feel about that?*

S: Well I am very antagonistic about all that. Even though I managed to keep my breast for another five years after my first diagnosis, it was worth it. Within eighteen months of my first diagnosis I was diagnosed with another tumor. Three years later I was diagnosed with another two tumors. At that point I was ready to have my breast removed.

*M: The next question really looks at any major events that have taken place since being diagnosed with breast cancer.*

S: You really question everything when cancer strikes. That's the one thing about a life threatening disease, you question everything and you look at things differently. There are certain things in my life that I never would have questioned had I not have had breast cancer. You know I have been married for twenty-nine years. But for the first twenty years I never questioned the marriage, never questioned the relationship, never questioned what was going on in the relationship. When I got cancer straight away for the first time I started questioning my marriage and things have now changed in that relationship. Now there are certain things that I am not prepared to accept within the relationship. Before cancer I didn't ever question the problems I had in my marriage. I played dumb, closed my eyes and my ears to things in the relationship. But the moment I felt I really didn't have that long to live, or maybe there was a threat to my life, I changed in my thoughts. But of course I have spoken to other women whose changes have been more radical than mine. I don't have the courage to make complete changes. So the decision I made was quite a big one, but not as big as I would like and that's because of hurting other people. I am a businesswoman so I couldn't just pack up and leave. It would hurt too many people.

*M: Was that something you thought of doing, just giving it all up?*

S: Oh yes, oh yes, yes. That's a whole psychological thing we could go into. I should have made more decisions, but I did make some revolutionary ones. And one of the main ones was that I tried to be more selfish because I don't think women are selfish enough. I have my own life outside of the family now. I have a great bunch of girlfriends who I rely on a lot. Friendship was something I never gave much time to before cancer.

*M: Have there been any other major events?*

S: Pretty freaky things happened. When I had my breast removed it was pretty radical. They get down to the bone and there is not much left and you're sort of looking at yourself in the mirror. And I was always a booby person and that was quite hard to come to terms with. I am so much of a businesswoman that I wanted to fight

423 the situation I was placed in. I thought I am not going to sit like this. I feel a victim  
424 when I look in the mirror I am not going to be like that. So I took nearly nine months to  
425 research plastic surgery. My oncologist gave me some leads but it was very hard to  
426 get appointments with some of these people. In the end I found a guy who does  
427 cranium reconstruction and he is very much a caring person. And he did it and it was  
428 a great success. But, following that, I had four hernias because my stomach broke  
429 down so I was in hospital four times in one year. I soon discovered that whilst he  
430 might be a good plastic surgeon, he was a lousy surgeon. I remember one of the  
431 operations he carried out. I had asked him to take off a tiny lump I had on my chin.  
432 When I woke off he had taken my beauty spot off because he hadn't written on the  
433 right spot of my face. I loved that spot and he left me with a hole and he thought it  
434 was a laugh. I could have taken that to the cleaners, but I didn't.

435  
436 Going back to where I changed I have to say that I am still in a marriage where there  
437 is no emotion or passion and I always hid it. I still live with this wonderful man. I mean  
438 he is good and kind and a wonderful father and all those sort of things, but there was  
439 virtually no sex in the marriage. That was cool because there was so much more  
440 benefit in the marriage and he was a good man. Prior to breast cancer I would think  
441 to myself oh this is fine. So for twenty years of marriage I never said anything about it  
442 except to him and he couldn't change. So in fact three years ago I threw him out of  
443 the bedroom because I wanted my own space. That was definitely because of the  
444 cancer. He now sleeps upstairs and I sleep downstairs. I must make my own life now.  
445 I try to include him wherever possible, but generally speaking I make my own life  
446 now.

447  
448 *M: So your lives are separate, but you both live with each other?*

449  
450 S: Yes we live together and work together, but I try and do a lot of other things. I think  
451 maybe there might be gradual steps in the future. I might get a flat.

452  
453 *M: What things helped you to cope with breast cancer?*

454  
455 One of the most traumatic things with breast cancer when I was first diagnosed, and  
456 it only happened once, was the breakdown of a friendship. We had some pals who  
457 had children the same age as us. She was a real pal of mine and we used to see  
458 each other regularly. The moment I had cancer she wouldn't walk over the doorstep  
459 and wrote me out of her life. I never spoke to her about it. I thought it was her loss  
460 and I had a lot of friends anyway.

461  
462 *M: Were there any other friends that treated you like that?*

463  
464 S: No on the contrary I found strength and support through my friends. One friend of  
465 mine has an 'Occa' husband. Her husband is a successful businessman and a real  
466 rough diamond. A lot of people can't cope with him at all, but I've always liked him.  
467 He wrote me a letter that I have at home when I got cancer. I cried my eyes out when  
468 I read that letter. It was just so supportive and he virtually said that he and his wife  
469 would be there for me. That letter came from a man who on the surface you would  
470 think had no feeling at all...a powerful man.

471  
472 *M: When there are times when you feel threatened or are in pain how do you deal  
473 with that?*

474  
475 S: I have a very supportive daughter; she is an amazing person. She is into the  
476 warrior women. Warrior women are women who used to cut off their left breast in

order to pull the bow back. My daughter has given me big pictures of warrior women. Julie was very much into warrior women. She is an amazing girl.

*M: When you wake up in the morning and it is a new day, are there certain things that allow you to attain a sense of peacefulness and hope towards your illness?*

S: I am fifty-four and I have a new assistant now so I am hoping that I can leave the office at three or four in the afternoon. I do get up early in the mornings. Sometimes I walk for thirty minutes, sometimes I do yoga. I love mornings and I love the thought of a fresh new day. When I was first diagnosed and I got over it the first time I took on a trainer. He helps me with a lot of diet issues and a lot of vitamin issues and a lot of fitness issues. And I started running and pumping iron. Then with the hernia operations I had to stop. So it is only this year I was able to regain my strength and I am hoping to improve my fitness level next year and that is important to me. You know I wouldn't have had a trainer if I hadn't have had cancer. Somehow I wouldn't have been selfish enough. I consider having a personal trainer selfish and self-indulgent and now I can justify doing things for myself.

*M: The last question is has there been any kind of faith journey since being diagnosed with breast cancer?*

S: None whatsoever. In fact I am anti-religion, even more so when I got ill because I would have felt it hypocritical. I find the elderly and the sick going to religion when that time occurs totally hypocritical. In fact I am quite antagonistic towards it because I think you are what you are and your using the system because a bad time has struck you.

*M: And what about your spirituality? Do you get that from work or yoga?*

S: I have painted in the past so I wouldn't mind going back to doing some oils, or charcoal work. I do love this path of fasting and this different alternative style of living. It makes you feel clean. This feeling comes from the yoga so I suppose it is sort of spiritual, yeah it is spiritual because I love it.

**Rebecca**

*M: Tell me about your breast cancer. How did you come to find out about your illness and how did you feel at the time? You said that in 1983 you felt a lump in your left breast.*

R: It was just an accident I don't know why I went to the doctor. I wasn't feeling too well. The doctor found a lump in my breast and booked me for a mammogram. He then organised for me to go to the surgeon. On the Wednesday before it I rang my G.P. He said he would come and be there. I asked him to do a smear test because I was late with my period. Following the smear test I went to visit my doctor and he told me I was eight weeks pregnant. I was thirty-seven and I didn't know. My period had been erratic over the years and for years we had tried to have a baby. We couldn't have one so I had given up. I also found out that I had a benign tumor in my breast and had an operation. My baby survived.

*M: You must have been happy that you were pregnant?*

R: Well I was in a state of shock with this lump you see because had it of been cancer I would have lost the baby. I had a mammogram every year following this. It was during my ninth mammogram that they found a lump. I then did a needle

531 aspiration—a biopsy and had a partial mastectomy. My friends were so supportive. I  
532 don't drive and they would drive me to the hospital were I was having treatment.

533

534 *M: How did you feel this time around when they told you that you had cancer?*

535

536 R: I don't know I just sailed along. In fact Macey my girlfriend came into the hospital  
537 with me the day I found out that I had breast cancer. I said to my husband, "Oh don't  
538 take the day off work I'll be all right". And I don't know why I did that, why I never got  
539 him to come. I suppose I wanted to protect him from it.

540

541 *M: When they told you that you had breast cancer, what was your reaction?*

542

543 R: Fine. Yet I don't know when I had reached a stage where I had had enough. I then had a  
544 nervous breakdown. You see I am usually a strong person, but I think it was all the  
545 build up of the pain with the back and the groin. But I never ever thought I would be  
546 the type to have a breakdown. I have since found out that breakdowns can happen to  
547 any one. I had a high tolerance of pain and that pain was dreadful. I did have a fall  
548 whilst I was in hospital and this added to the pain. I just thought cancer was  
549 something that would go away. Another thing was I had to give up work. I had a little  
550 job that I really enjoyed. I am a recorder for weight watchers and when I couldn't do  
551 that anymore I got really depressed. I think that led to the breakdown too because I  
552 was home all the time and I really wasn't well enough to go out or work.

553

554 *M: Can you please describe some of the other feelings you encountered whilst at*  
555 *home on your own.*

556

557 R: Well I just felt so ill and I wasn't used to feeling so unwell. I think that's what  
558 affected me. Joe, my husband, was very good. My son was also very good as well.  
559 His teachers were good too. His homeroom teacher rang up to see how I was. Now  
560 the cancer has returned in my ribs and I rang her to keep an eye on him. She said  
561 she would. And his R.E teacher Miss Ryan was very good. This helped me so much  
562 because I knew that he would be watched over. And do you know what he is positive  
563 he doesn't think that I am going to die. Which is good because I worry about him. He  
564 is not depressed. I just think he thinks I will always be there. He doesn't think about  
565 the negative effects of cancer.

566

567 *M: And what about your husband?*

568

569 R: Yeah he is pretty good. I don't think that he thinks I will die because I have always  
570 been so strong.

571

572 *M: So do you talk about your illness?*

573

574 R: No we don't really talk about it.

575

576 *M: Does that bother you?*

577

578 R: No not really because if we kept mentioning it, it would always be in the air and I  
579 would prefer it not to be like that.

580

581 *M: So you prefer to talk in your cancer support groups?*

582

583 R: Yeah I talk a bit, but I really don't want to dwell on it.

584

585 *M: If you don't want to dwell on it why do you keep going to the support meetings?*  
586  
587 R: I go to help others because when I had cancer there was no-one there to help me.  
588 I also go to the meetings because I want to find out a few things too about the  
589 treatment different women get and all the rest of it.  
590  
591 *M: Now that your cancer has come back are you taking a different approach in these*  
592 *support groups? Do you see the support group in a different way?*  
593  
594 R: Yeah well I can see things happening and I can learn from them too. Whereas  
595 before I was there for them and now I listen. I suppose everyone is different.  
596  
597 *M: Were there any major events that took place after you had cancer?*  
598  
599 R: Menopause. I had been going through that a bit before hand but the hot flushes  
600 are dreadful and embarrassing. Especially when you're out and all of a sudden you  
601 start to perspire. You feel so much and when I am out I ask Jill if she can notice and  
602 she says she can't. And when I am at the weight watchers meetings I say, "Oh it's  
603 hot". Sometimes it has been hot, but I have been hotter. And that was one of the  
604 reasons why I put off taking this tamoxifen because I have to live now. When I sweat  
605 I feel uncomfortable and I am worried about my make-up. The side effects may  
606 cause me to sweat.  
607  
608 *M: Please tell me about your breakdown. What happened?*  
609  
610 R: I just got so frightened to go out. I started crying and I don't know really why. I was  
611 worrying about all silly things, financial things. Being here on my own and not being  
612 well everything got on top of me. I had no support groups; I had no-one to talk to.  
613 Maybe if I had of gone to the support groups from the start I would have been all  
614 right.  
615  
616 *M: What about your friends at this stage?*  
617  
618 R: Yes. Jill tried to help me but I needed to be around people who were experiencing  
619 the same thing.  
620  
621 *M: And so you were upset, you were feeling more isolated, more alone. Did that lead*  
622 *you to seek help?*  
623  
624 R: Yes. There was one friend who had been through a breakdown and she was on  
625 nerve tablets and I spoke to her and she was a big help. And I knew that I needed  
626 help, it wasn't me. I think at one stage I thought, "I wish I was dead". It is dreadful to  
627 think that. I didn't care if I lived or died. I went to the G.P and he knew it wasn't me. I  
628 went into the Melbourne clinic and I didn't want to be in there. I saw all the other  
629 people who had breakdowns and I thought I don't belong here. I came home and  
630 then it got on top of me and I went back to the clinic and I must of thought about it  
631 and I thought I am getting out of there otherwise I will end up like them. So from then  
632 on I went back to weight watchers and went to work. There is a lady who does the  
633 Wednesday night meeting. Her name is Macey. I got her number and then I found  
634 out about this support group up at a hospital. I had only been to a couple of meetings  
635 when I met you and they are a nice group of ladies. This American friend of mine  
636 came to the group and she said they were nice.  
637  
638 *M: Tell me how you felt when you first went to the meetings?*

639  
 640 R: When I first went to the meeting I was scared. I thought I was going to cry you  
 641 know. I didn't know the people and I didn't want to cry. And they were so nice that I  
 642 thought I wish I had of gone their sooner and I wish I had of. I think that all women,  
 643 who have had breast cancer, if they can handle it, should get counselling. They  
 644 should be spoken to in the hospital because I wasn't. My counselling came through  
 645 the support group and then I got on top of it too. I did some research and stuff and  
 646 started reading up on books and that helped.  
 647  
 648 *M: Did the support groups suggest any methods for coping that you hadn't previously*  
 649 *used?*  
 650  
 651 R: I don't think so. I just got on top of it myself and decided I just had to move on.  
 652  
 653 *M: Were there any other major events after the cancer, things that you hadn't really*  
 654 *addressed prior to being diagnosed with breast cancer?*  
 655  
 656 R: No not really. Everything was o.k. The recovery of my breakdown was a major  
 657 event.  
 658  
 659 *M: What do you do when you feel threatened or in pain?*  
 660  
 661 R: I think I am in a state of denial. I have the pain now and I think to myself well I just  
 662 have to live with it at the moment.  
 663  
 664 *M: Is that denial or acceptance?*  
 665  
 666 R: I suppose it is acceptance too. I think I was in denial about getting the cancer back  
 667 where as now I think this is just acceptance. I just have to put up with it as long as  
 668 the pain isn't too bad and I am sure there are things they can do. Usually I keep  
 669 myself busy. This girlfriend of mine Jill, she has a little baby and she has four  
 670 children. Jake her five-year-old son has Down Syndrome and I help her a lot. He has  
 671 just started school and when she needed help to go to the hospital I would go with  
 672 her. That makes me feel good and Jill and I do a lot together. I like the gardening and  
 673 I have since got a cat and she is company. And the day I had my bone scan I had to  
 674 have my last cat put down. For two years I didn't have one. Now my cat is company  
 675 too. I go for a walk up the street, do housework and speak to friends on the phone. I  
 676 am grateful for my life and I take each day at a time.  
 677  
 678 *M: Has there been a faith journey for you?*  
 679  
 680 R: I believe in God and give thanks to my life and I realise how lucky I am. Although I  
 681 am not rich, I am rich in other things. I have good friends and family. I became a little  
 682 more religious once I was diagnosed, but I don't go to church every Sunday. I do  
 683 have a sense of God. I am not scared of dying. I know that might sound morbid.  
 684  
 685 *M: Why are you not scared to die?*  
 686  
 687 R: I'm just not. I see dying as something that happens. Having this approach to dying  
 688 helps me cope. We used to go out for New Years Eve to a party and our parish priest  
 689 used to come. He got cancer and died a couple of weeks ago. We thought he'd  
 690 beaten it and he hadn't. Then I thought it could strike anybody. It doesn't discriminate  
 691 or anything like that. And I think well I will be all right.  
 692

693 *M: The fact that you are not scared to die, is that a reflection on your life till now?*

694

695 R: I have had a good life. I went overseas when I was young. I married later and had  
696 my son. The only thing I wouldn't want is to die in pain and without dignity, but I have  
697 had a good life. That could be it. There are no regrets. I am happy with my life. I don't  
698 know how other people think. At the meeting on Monday, this lady Jocelyn came.  
699 She is very nice, but she lives in dread everyday of the cancer coming back. She was  
700 so upset and I invited her down here for coffee and um she wanted to come and on  
701 the Friday I had to cancel. And she isn't coping at all and she was in a terrible state  
702 and I was never like that. It must be hard for different people how they cope. She has  
703 had her cancer and can't put it behind her. I have put the cancer behind me

704

705 *M: But what about your breakdown?*

706

707 R: Yeah I suppose that was a troubled state. Yeah I can't remember how I was. And I  
708 don't think I talked about it. I was at home at the time and that made things worse.

709

710 *M: Please tell me about your body image.*

711

712 R: I had a partial mastectomy and it wasn't too bad really. The surgeon did a good  
713 job. He has done a very good job. When I look in the mirror I think gee it's not as bad  
714 as what I imagined. I have been married for twenty-four years and it doesn't bother  
715 my husband. I don't know how it would be for a young girl. A few doors up there is a  
716 young girl. She is a teacher. I wonder how it effects her because she is Italian. My  
717 actual breast looks o.k. Ral had a full mastectomy and I think it affects her. Mine was  
718 a partial mastectomy. Ral only found out on Monday about bathers. She has to get  
719 special ones to go swimming. Sometimes I look at people who have had accidents,  
720 you know the paraplegics and I think well I shouldn't complain too much.

721

722 **Samantha**

723 *M: Please tell me about your journey with breast cancer. How did you come to find*  
724 *out about it and how did you feel at the time?*

725

726 S: I was lying in bed one night and I found a lump on the right side of my breast. I  
727 was working that time late at night with a friend at a university and she was a health  
728 worker. I was there the next morning and I told her about the lump and she asked me  
729 to show her and I did. She went berserk and said you have to go to the doctors  
730 straight away. I thought this was incredibly inconvenient. I thought the lump was a  
731 cyst as I had been really tired and run down. Within a day and a half I made an  
732 appointment with a G.P. I went in there one day and was lucky that the woman I was  
733 seeing specialised in women's health and she was very nice. When I went there she  
734 said it was really unlikely that it was anything because of my age. Her opinion was  
735 that it was a cyst. But she wouldn't let me leave the surgery until I made an  
736 appointment for a mammogram the next morning. I had the ultra sound and then  
737 when I was getting dressed they said that my G.P was on the phone and she asked  
738 me to see her. I went to see her and at that stage I realised there was something  
739 wrong and the tears had started. She told me that the ultra sound was weird and I  
740 had to see a specialist, a surgeon. In the afternoon I had a needle aspiration. By  
741 Monday I found out the results and it was frightening because you didn't know what it  
742 meant. I was thirty-two at the time. It has almost been three years at the end of  
743 November. I was told that I had breast cancer. They did a partial mastectomy and I  
744 went to a private hospital. I was really angry afterwards because they rushed us into  
745 having private health cover.

746

747 *M: What was wrong with going private?*

748

749 S: It costs three thousand dollars and I was only in there for a couple of days. I came  
750 home with the drain still in. There is that financial pressure as well with private health.

751

752 *M: How were the nurses and staff?*

753

754 S: Shocking, they were terrible

755

756 *M: In what way?*

757

758 S: They just didn't seem to know what they were doing. It was incredibly haphazard.  
759 It was really strange in there. It wasn't what I expected a private hospital to be. I  
760 shared the room with one other person. At the hospital I was at the staff looked like  
761 travellers. They had uniforms, but they would come into the ward with leather around  
762 their necks and beads; they didn't look professional. They didn't even know what had  
763 happened to me, and what kind of surgery I had had. It was really strange. It is all a  
764 bit hazy. I remember I would order my meal and I never got what I ordered. I had no  
765 choice about what I ate. I was put on pethadine to numb the pain I was feeling. Once  
766 when the nurses had a changeover in shifts I had to tell the new nurse what to do. It  
767 was something really odd in that she didn't know where to put the needle. It was  
768 really strange. It was almost like they were temps and they had come from an  
769 agency. I remember one day they said, "Oh you can go and have a shower now".  
770 There was this drip stand that I was attached to. I said, "How?" They said "Just take  
771 the drip stand with you". That was awful. I went into the shower and when I saw  
772 myself with all my bandages and stuff I just cried. I was so upset and I was just  
773 howling. Then they came in. I hadn't seen myself in the nude since the operation.

774

775 *M: That would have been very confronting for you.*

776

777 S: That was horrible because at that stage I didn't know what had happened. The  
778 surgeon didn't come back after the operation to tell you how everything went. All he  
779 said was that everything went well and then he left. The next time he didn't come,  
780 someone else came and it seemed confusing. Because the operation went well they  
781 thought I would cope. The support that they offered was next to nothing. The  
782 physiotherapist came around to tell me what exercises I had to do when I got home.  
783 She gave me a photocopy of some exercises I had to do. She didn't actually go  
784 through them with me and I lost the photocopy. When I came home I was really sick.  
785 I had the drainage in so I had to go back on the Monday to get that out. I went by  
786 myself. I caught a cab. I came home and the pethadine started to wear off and I  
787 threw up everywhere; it was so painful. It was really hard because the only person I  
788 had was my husband because my family is not here and his family is odd. His family  
789 wasn't supportive. They hadn't spoken to me since I had come to Melbourne so there  
790 was always this tension between them. When I was sick they did this big turn around.  
791 They started to be nice to me and I felt confused because his mother hadn't spoken  
792 to me for four and a half years. She decided I wasn't the most appropriate girl to  
793 marry her son.

794

795 *M: Has your relationship since improved?*

796

797 S: Yes it has but it has caused a lot of emotional upset for me because they have  
798 never apologised for their behaviour. They think everything is fine now and they are  
799 so demanding. They will ask my husband why I didn't come to dinner? Why I don't

800 want to be a part of the family? And I think it is really hard to take considering they  
801 didn't want me to be apart of the family in the first place for four years.

802  
803 *M: So has breast cancer changed your attitude towards people?*

804  
805 S: Yeah it does change things. You feel differently. You feel things are more black  
806 and white, there is less grey. Now things are either in or out. I am a really generous  
807 person, patient and interested in people. I usually try my best and I do think people  
808 have something to offer. When I first met my husband's family I thought they were  
809 unusual and that was fine until they started to be quite nasty to me. That was  
810 upsetting and now they are nice, but I don't trust them. I am really scared. I also  
811 associated that stuff about being sick with having moved to Melbourne and dealing  
812 with people that didn't like me. I was always being excluded. Then you get sick and it  
813 is hard not to think there is a link between stress and getting unwell.

814  
815 *M: Do you think all this pain was the cause of your breast cancer?*

816  
817 S: I definitely thought that to start with. I think now it is one of the components. I  
818 certainly think if I didn't have that emotional stress there would have been a good  
819 chance that I would not have had breast cancer. Now I find it difficult to trust people. I  
820 also blame myself for allowing people to affect me so much. I should have been more  
821 careful about myself and wary about how people were treating me. I can't believe I  
822 was so gullible. I can't afford now to give my care in the same way I did before. I did  
823 pick up well then after twelve months I went way down hill. I guess the other thing  
824 that happened is I didn't have after-care. I was left to my own devices. My specialist  
825 wasn't supportive. He felt good about my development and that my scars were  
826 healing up, but that was all he was interested in. I would ask him questions and when  
827 he answered he was condescending to me. He treated me as though I didn't know  
828 anything and he knew so I should just believe him. To start with I coped quite well.  
829 You expect not to be well for a certain length of time. I think it was really difficult for  
830 my husband. He wasn't very supportive although he thought he was which was  
831 difficult. His idea of cooking dinner was to get take-away and he wouldn't get those  
832 until nine at night. It was just terrible and I felt very uncared for.

833  
834 *M: Were there any major events that occurred since breast cancer?*

835  
836 S: I have lymphodema and one of my neighbours told me about the young women's  
837 group who meet for dinner once a month. I got the number off her and that was the  
838 best thing. I went to Europe and that helped and that was great but at that time I had  
839 started to realise that the swelling in my arm hadn't gone away. I was really tired  
840 anyway and when I came back the group told me about the lymphodema clinic. They  
841 told me about this clinic. The first time I went there was great. I had rung up the  
842 cancer help line, which was good. I desperately wanted to have some counselling  
843 because I was really angry about all those things. I ended up seeing someone who  
844 was doing her post-grad in counselling. She was nice but you don't know what it is  
845 like until you have it. So when I went to the group they said tell us your story and  
846 they told me about all these professionals who were really good. They told me about  
847 lymphodema and I thought there is so much information out there that I am ignorant  
848 of.

849  
850 *M: Were your friends supportive?*

851  
852 S: I had moved out from Sydney so I don't have a lot of friends. Those friends I have  
853 now I have only known for a year or two. It is really hard to ring up someone and ask

854 them to do my washing and clean my house, so I never asked anyone to do  
855 anything. My mum didn't tell anyone and she thought I would get better. She is a  
856 great woman, my parents are nice, old fashioned and uncomplicated. My relationship  
857 now with my husband is a lot stronger. His family is emotionally manipulative and he  
858 has often been bullied into picking them over me. I think he looks back and he thinks  
859 he could have done a lot better. He has changed his behaviour.

860  
861 I think breast cancer changes your whole lifestyle work wise. I would be more  
862 selective now in the work I do. When I first came to Melbourne I was a receptionist at  
863 a factory site and I wouldn't do something like that now. We needed the money but it  
864 wasn't my choice. I wouldn't do that now. Life is too short. Life is not the same  
865 though. It wasn't like a transformation like wow I didn't die so now I have to be  
866 thankful and happy. In fact I went to the other extreme. I became really negative and  
867 I guess it is all that culling and realising that stuff you don't want in your life and  
868 thinking if I want to sleep until midday I will sleep until midday.

869  
870 I guess the thing is I get frustrated with people who don't understand. I had some  
871 friends who behaved really badly towards me one night. I wanted to go to bed and  
872 they didn't want to go home. It was New Years Eve and a friend had brought over  
873 some of her friends. I was asking her politely to take her friends and go home and  
874 she wasn't ready to do that. I was so tired I turned the music off and said, "Right  
875 that's the end go home". They reacted so badly to me afterwards like I had let them  
876 down by kicking them out. I don't care any more. That was the first time in my life I  
877 had ever did that and I wasn't going to apologise. I thought they had been unfair. I  
878 am a much stronger person now. When you have cancer you have to confront  
879 yourself, what you think and what you feel. You have to take a lot more responsibility  
880 for what happens to you in life. If you don't like something you have to say no rather  
881 than complain about it.

882  
883 *M: When you feel threatened, or in pain, or anxious, what do you do?*

884  
885 S: I get upset. I don't do meditation or relaxation. I have been taking Chinese herbs  
886 to clean out my system. The Chinese herbalist I see promises to get rid of my  
887 lymphodema. A friend of mine takes Chinese herbs and said I thought I should give it  
888 a try. Many people have recommended I do yoga, or meditation and that was so  
889 mind-boggling. I started to get depressed and overwhelmed by everything and I am  
890 sort of coming out of that now. From the lymphodema clinic the social worker said I  
891 might have depression and they said I should go see my G.P. I went to a G.P and he  
892 was good and he knew what lymphodema was so that was great. He put me on a  
893 tablet at night. It is a sedative and a painkiller and immediately I started to sleep. I  
894 started to get better because I think I had been through twelve months without sleep.  
895 The herbs after three weeks started to work and my mood just changed. I don't know  
896 whether it is the ritual of doing something that is good for you, but I stopped crying  
897 after two and a half weeks. Prior to this I used to cry everyday and I haven't really  
898 cried that much. Before I would spend whole weeks feeling sad and negative. So  
899 there has been a progression. Then I started working on a committee for young  
900 women with breast cancer and I write the press release. I would never work for  
901 something that is futile.

902  
903 *M: Please tell me about your faith and spirituality?*

904  
905 S: I grew up in an Anglican Church. All my life I have tried to get away from the  
906 church. I guess I believe in a God or Universe, but not religion. I have a belief in  
907 spiritual guides from experiences and that helps me. I believe that all the time I had

908 spirit guides with me during my illness. I have always felt watched over. One night  
909 when I was asleep I got a distinct impression that my inner voice was saying you  
910 better have the radiotherapy because it is not all gone and there is something still in  
911 there. I am in tune with my body and I am very sensitive. I was in bed one night and  
912 my sharkras started to light up and this energy was running through me. I thought  
913 wow and I got the feeling that whatever was left in my body was gone. I felt  
914 everything was fine. I had another inner voice tell me my cancer was back, that it was  
915 there but no one could see it yet.

916  
917 *M: How does that make you feel?*

918  
919 S: For the first little while I was panicking and I was feeling depressed. I get confused  
920 about what is real. That's when I started the Chinese herbs and that made me feel  
921 better. When I told people that I thought my cancer was back, people reacted so  
922 badly and said, "You can't think negative thoughts, that will bring back your illness".  
923 And I think what does it mean? Because I am negative do I create my own illness? I  
924 think that people are odd. So now I am not sure whether it is a warning that if I am  
925 not careful it will just flare up. I believe one of my spirit guides is a Chinese man.  
926 They say you have one that stays with you your whole life and then throughout your  
927 life you have others that come when you need them as they come with different  
928 skills. You can have a lot of them. They are like guardian angels and I feel a sense of  
929 relief. So that has always been my thing that has kept me feeling good. I do think that  
930 there is a bigger plan.

931  
932 *M: Please tell me about your sexuality?*

933  
934 S: Yeah that is a big thing. It is very hard to get excited about sex because there are  
935 all sorts of things involved now like pain. Even my husband used to rub me on my  
936 back and that would make me feel nauseous and things began to hurt. So you can't  
937 get past that. I feel that my breast is out of proportion to the other. Basically it has  
938 healed up well, but the effect is that you feel kind of odd when you look at yourself.  
939 For a long time it was enough to make me cry, to see that scar and your lob sided.  
940 Now it is not really that bad.

941  
942 *M: How did you come to grips with that?*

943  
944 S: The first time I went to the support group I spoke to one of the co-coordinators and  
945 I said something about getting back to normal. She said, "Are you still waiting to get  
946 back to normal?" And I said, "Yes". She said, "Samantha you will never get back to  
947 normal". I went home and that made such an impact on me; that was hard to deal  
948 with. I got upset about that. It was true. I started then doing things for myself like  
949 being selfish. Another thing is that my husband wants to have kids and I find that not  
950 an exciting prospect. I wanted kids before but now not so much because I am tired.  
951 The whole idea of being sick and another fifteen or twenty years of looking after  
952 someone else doesn't excite me. We were always in two minds about the whole idea.  
953 Some people get lymphodema when they get pregnant. Being pregnant can feed  
954 tumors that like estrogen. You don't know what side effects you will have. They do  
955 say that young women who get pregnant after cancer do better because they are no  
956 longer operating in survivor mentality, they have something else to nurture and get  
957 on with and look after. I can see that.

958  
959 **Sharon**

960 *M: Please tell me about your journey with breast cancer. What happened when you*  
961 *were first diagnosed?*

962

963 S: When I first diagnosed they called me up again because it was my second  
964 mammogram and they said there was something there. I eventually had an ultra  
965 sound and a test with the needle. The results came back positive. So they had to call  
966 in the surgeon and I had to make an appointment with him. My greatest complaint  
967 about the surgeon, and there are lots of complaints with surgeons, is that he told me  
968 the types of surgeries available but he didn't tell me the kind of problems I could  
969 expect with each type of surgery. It wasn't until I was in hospital that all the nurses  
970 there said that in most cases women come back after surgery. I was back in there  
971 three times with infections after my partial mastectomy. It was just awful. I was  
972 bleeding profusely. One day they had to lance the wound it was so bad. That's what  
973 annoys me. I say to all of my friends who get breast cancer to get the whole breast  
974 off and not muck about. I suppose I am different. I suppose I don't really care that  
975 much, but there are probably women out there more vain than me. But, I would  
976 recommend that.

977

978 *M: When they told you that you had breast cancer were you all right? How did you*  
979 *feel?*

980

981 S: I was all right. It was a shock and when I went to the breast cancer screening the  
982 girl said to me, "Out of all the women we have called back in we thought you wouldn't  
983 be one of them". She told me how sorry she was for me. There was a social worker  
984 who was there you know. They always counsel you afterwards when they tell you  
985 about your diagnosis. When they told me I was pretty blasé I suppose. I wasn't really  
986 phased out. But, when I went to see the surgeon to discuss the operation I took a  
987 girlfriend with me because I just didn't know what to say. My girlfriend spoke for me  
988 and said what if she had this, what if she had that and he said, "You have the option  
989 of having the breast off, you don't need radiotherapy". There was also a counsellor  
990 there when I went for the screening and she was pretty good. Yeah she was lovely  
991 absolutely lovely. She comforted me. All I thought about when they told me was I  
992 won't see my grandchildren grow up.

993

994 *M: Have there been any major events that have taken place since breast cancer?*

995

996 S: No my life has been pretty boring. I don't work any more. I do have other health  
997 problems too. I now attend a support group for women with breast cancer. The girls  
998 are so nice in our group they are good fun. We have a lot of members in our group.  
999 We are more casual and laid back, but caring. We all ring each other. I have been  
1000 with the group for three years now. I went as soon as I had my operation. My  
1001 operation was three years yesterday. In our group we have Kim. Her mother-in-law  
1002 came to the group to find out how she could help her daughter. Kim is having a hard  
1003 time coping at the moment. And the president is a blind lady and she is partially deaf.  
1004 Her husband is blind and has cancer of the bones and there is nothing they can do  
1005 for him. I look at them and think I am fine. I mean I can't understand why Kim can't  
1006 see the same thing. Kim is seeing a psychiatrist too because she had a nervous  
1007 breakdown after breast cancer. What I can't understand is that she has so much  
1008 support. I mean she has this wonderful husband. I had no-one except my daughter  
1009 and she wasn't even here she was in Cairns. I guess everyone is different

1010

1011 *M: Do you think the way you cope with your illness may be dependant upon the*  
1012 *stage your at?*

1013

1014 S: No I don't think so because we have ladies there who have had their operation  
1015 eight, ten, fifteen years ago and they still have problems, especially the elderly ones.

1016 They have health problems where things are coming back related to their cancer. But  
1017 the majority of them are good. But, Kim I worry about her. I am happy. I have been  
1018 divorced since I was thirty-six so I am very happy. I have a young guy boarding here  
1019 and he is pretty good. I don't think I would get rid of him and he is gorgeous.

1020  
1021 *M: What do you do during times when you feel threatened or in pain?*

1022  
1023 S: I just keep it out of my mind. I am still in pain three years later. The last time I saw  
1024 my professor, who is gorgeous, he told me that he wasn't happy with my boobs. I still  
1025 can't lie on my left side. Some girls have reconstruction and some don't. Our  
1026 treasurer is gorgeous. She had these huge tits and they took one off. She eventually  
1027 had her breasts reduced and was happy. No I don't think I could be bothered. But  
1028 everyone is different. Some women think it is important, but I think it also depends on  
1029 if you have a partner and what your partner thinks about it. Some partners might  
1030 think, "Oh she's not a woman because she has only one breast!"

1031  
1032 *M: What would you think if you had a partner like that?*

1033  
1034 S: I wouldn't care. I must admit I shed a few little tears when I went to work and they  
1035 asked me how it was going in the hospital. My daughter and her cousin and all the  
1036 young girls were there and they took me there and that was the most beautiful thing.  
1037 At that stage that's when you need people there to guide you, people who care.  
1038 That's the most important thing people caring.

1039  
1040 *M: One of the questions was sources that helped you to cope and you just mentioned*  
1041 *people and caring and you also brought up your grandchildren.*

1042  
1043 S: Yeah and also my daughter didn't say, "Ohhhh how are you mum?" like that. She  
1044 didn't dwell on it and still doesn't and I think that that has helped me a lot. During my  
1045 illness she never once said, "Oh you poor thing". She is positive and doesn't treat me  
1046 differently. I also love to garden and so a lot of walking. I walk two kilometers in the  
1047 morning without my dogs and then I come home and take them. I do a fast walk. I  
1048 have done it for about six years and once you do it you just love it. It was hard getting  
1049 up when it was two degrees but my poor neighbour. I wake her up and she comes  
1050 with me. But if she doesn't go, I go on my own. So yeah even when it is two degrees  
1051 I still walk. I love looking at gardens and houses. You can turn off from everything.  
1052 You know gardening is like that I just turn off from everything. I have pure compost  
1053 and I must have one thousand tomato plants coming out of my compost bin. Last  
1054 year I had forty kilos of tomatoes from one bush. The ethnics across the road say,  
1055 "You reckon we're wogs!" I have tomatoes in the front garden, capsicums in the front  
1056 garden. I grow garlic and roses. When I reflect on my illness I don't look at it in a  
1057 negative way. It was just something that happened. I had the support of my daughter  
1058 and family. When I wake up in the morning I have a sense of peacefulness. One of  
1059 the nurses in the hospital use to say to some of the patients when you get up in the  
1060 morning say, "I am beautiful". Look in the mirror and say, "I am beautiful". She was a  
1061 fantastic lady.

1062  
1063 *M: Did she give you any other tips that you found useful?*

1064  
1065 S: Lots of things. She was helpful in telling me things that I don't think a lot of patients  
1066 get told. A lot of surgeons don't really know much about lymphodema, even the  
1067 medical people. Like you go for a blood test and I tell them not to take it from my left  
1068 arm. And they look at you as though you are stupid. I have to then explain to them  
1069 that I have no lymph nodes in my left arm. But they should know and question this,

1070 but they don't. A lot of girls who have gone to hospital after their operation have had  
1071 to fight with nurses in the hospital. Some nurses think it doesn't really matter and it  
1072 does. With the lymphodema you have lost all your protection in your left arm so it can  
1073 be dangerous. I was never sick until I was fifty, never. I worked all those years from  
1074 when I was fifteen and I never had a sick day off. Once I turned fifty everything  
1075 happened to me. It was osteoporosis and then the cancer. I couldn't believe it. I  
1076 thought God is saying to me, "Listen mate you had a good run, it's about time you  
1077 start suffering". It's really weird isn't it, but never mind I cope. That's why I walk a lot  
1078 too because it keeps my feet moving because when I get up I am pretty stiff. They  
1079 say you have to keep active. The ostio is different because if I fall over I could break  
1080 a hip. I do try and eat well.

1081  
1082 *M: The last question is please tell me your faith journey.*

1083  
1084 S: I am a Christian but I don't go to church. I am a strong believer, but it hasn't really  
1085 helped me. My daughter and my friend have helped me a lot. My work friends are  
1086 fantastic. I have been very lucky.

1087  
1088 **Beth**

1089 *M: The first question is please tell me about your journey with breast cancer.*

1090  
1091 B: My first knowledge was in October 1965. I went to the doctors for a routine check-  
1092 up and they found a lump. We were living in England and we were coming out to  
1093 Australia. I had to have a medical examination. It was there when they found my first  
1094 lump. I went to the doctors and he sent me to a specialist and they said to go to the  
1095 hospital on Tuesday morning. In the hospital they came around with some students  
1096 who pressed and pushed. I couldn't feel anything, but they did. And just before I was  
1097 going to have the pre-med the sister called me into her office and said there is a  
1098 possibility of the breast being removed. She said we will take this lump out and if we  
1099 think it is malignant we will remove the breast. I shook, I didn't think of it. Breast  
1100 cancer that time wasn't so prevalent as it seems to be now. They removed the lump  
1101 and I had a tube in for some days and that was the first time I heard about breast  
1102 cancer. I came to Australia in 1976. I was all right when I was working but every time  
1103 I sat I felt a pain. This went on for three days. I didn't say anything to my husband  
1104 and I went to the doctors and I said to the doctor, "I have this pain as though  
1105 someone keeps sticking a pin in me". He sent me for a mammogram. The next day I  
1106 went back to get the results and the doctor handed me the x-rays and a letter for the  
1107 surgeon. He didn't say what it was. Then I had to tell my husband that I had been to  
1108 the doctors and what it was about. When we went to the surgeon my husband said  
1109 he would come with me. The surgeon looked at the x-rays and told me that I had  
1110 cancer in my breast. The surgeon said, "It has been my experience that a partial  
1111 removal is no good, a complete removal is necessary". And that's how it happened.

1112  
1113 *M: And so ever since then you have had your regular checks.*

1114  
1115 B: Yeah I have had two more lumps taken out of my breast, but they have been  
1116 benign. Every year for the last ten years I have gone for mammograms and checks.  
1117 But I am not going any more, I don't want to know. I am eighty-one and I say let  
1118 nature take its course. If it is or isn't, it is up to nature.

1119  
1120 *M: So you have resigned yourself to the fact that if you are going to have cancer you*  
1121 *will and it is a part of nature.*  
1122

1123 B: That's it. I don't worry about it. I never worried about it. I was sixty-seven when I  
1124 had my mastectomy done and I can understand it must be traumatic for young  
1125 women.

1126  
1127 *M: And you didn't find it traumatic at all?*

1128  
1129 B: No my husband was ten years older than me. He died a couple of years after that  
1130 in 1988.

1131  
1132 *M: Did you think about aspects to do with body image? Your breast came off, how*  
1133 *did that affect you?*

1134  
1135 B: Well I knew I wasn't whole again and I wanted to look whole so I used to make  
1136 pads. I couldn't wear a bra for a long time and I pinned the bra inside my singlet. And  
1137 I have inserted these pads in my bra for quite a few years now. I have been like that  
1138 since 1986. They did give me a prosthesis, but it was terrible. You put it into your bra  
1139 and it shifts and it moves. Your walking along the street and up it comes and you  
1140 can't put any pins in it because it would puncture it. So that's my way of dealing with  
1141 it. My daughter says to me, "Mum I never think of you as having one breast", so my  
1142 appearance doesn't give that impression. I didn't have to have any further treatment  
1143 or chemotherapy or anything like that. The doctor told me he got it all out so that  
1144 made me feel confident.

1145  
1146 *M: Do you regularly attend support meetings?*

1147  
1148 B: Yes. I didn't until I came to this retirement village. There is a lady here who used to  
1149 go and she had problems because she got lymphodema. One day she asked if I  
1150 would go to a support meeting with her. Well I hadn't gone before because I really  
1151 didn't want to talk about it, it wasn't of great interest to me. So I agreed that I would  
1152 go with her. I like to go to the meetings for the younger ones who have breast cancer  
1153 so they can see an older person who had it and got over it. I want to give them  
1154 encouragement. I have been going there for I think eighteen months.

1155  
1156 *M: How do you find it when you go there?*

1157  
1158 B: I feel very sorry for the young ones. With me my husband was ten years older than  
1159 me. We had been married for forty-four years at that time and we had a very good  
1160 relationship. Our sexual life was beginning to diminish as it does with old age and it  
1161 didn't bother us. My husband would always say, "Nature takes away from women  
1162 child-bearing because it would be a danger to her and it takes away the ability for  
1163 men because it could be a danger for them".

1164  
1165 *M: When your are speaking to young women or any woman that comes to you what*  
1166 *words of advice do you tend to give them?*

1167  
1168 B: Well I don't really give them any advice. We have a thing where we say how we  
1169 are. I say I am all right now for over thirteen years and I feel all right. These young  
1170 women have different ideas. One women that came in there has two young children  
1171 and she has had the breast completely off. She didn't have a bra on. You could see  
1172 she was very well developed and she had this large breast and then nothing. I think I  
1173 would have tried to avoid that, but that is their decision and I don't think I should put  
1174 forward my opinions of what I feel they should look like.

1175

1176 *M: It seems to me that you were comfortable with the removal of your breast. They*  
1177 *got all the cancer out and you were happy.*

1178  
1179 *B: Yeah otherwise they would have told me to have chemotherapy and radiation and*  
1180 *I had nothing.*

1181  
1182 *M: So in terms of body image you were o.k. You had been with your husband for a*  
1183 *while and he made you feel comfortable about your breast. You said you didn't feel*  
1184 *whole and your way of coming to terms with it was making your own prosthesis. What*  
1185 *about religion, was that a source of comfort for you?*

1186  
1187 *B: No I am not religious. I live for today and I feel o.k.*

1188  
1189 *M: Are there any things that help you, or make you feel good?*

1190  
1191 *B: No I just carry on day-to-day what I have to do and where I go. I go out with the*  
1192 *village bus a couple of days a week. I play cards Friday evening. Now I have*  
1193 *osteoporosis and I cannot do what I might have done if I was a younger woman.*

1194  
1195 *M: So you found that during the time you were first diagnosed you had a good*  
1196 *relationship with your husband and this helped. He was very understanding during*  
1197 *that time and you could talk to him if you had any concerns.*

1198  
1199 *B: Yeah. My daughter was very upset when it happened. My daughter and her*  
1200 *husband came the next day to see me. She said that her husband cried when she*  
1201 *told him over the phone. I think it would have made a lot of difference if I was*  
1202 *younger because your breasts are a part of your sexuality. So I was fortunate in that*  
1203 *respect.*

1204  
1205 *M: In 1986 after you diagnosis and breast operation, were there any major events*  
1206 *that occurred?*

1207  
1208 *B: Well what happened was we had booked a tour to go to West Australia and we*  
1209 *were to come back on the Indian Pacific. We were going in the beginning of May.*  
1210 *And I said to my husband, "Oh I don't know if I feel up to it". He said we would wait*  
1211 *and see how I felt when the time came. So when I came home I was so weak. I had a*  
1212 *small worktable in the spare room and as I sat there the perspiration rolled off of me*  
1213 *and the seat was all wet and I suppose it was weakness. I was so weak and I thought*  
1214 *I have to get my strength back some how. I lived in a block of units and I had to walk*  
1215 *down to the post-box. I told my husband that I would walk down to the post box and I*  
1216 *did that for two or three days. Then the next time I walked to the corner. Then I came*  
1217 *back and I gradually did that until I could walk all the way around the block, until I*  
1218 *could get my strength back. My neighbour used to take me out for a drive and I had*  
1219 *to sit with cushions because I couldn't bear the vibrations of the drive. I enjoyed the*  
1220 *drives with my neighbour. We would stop somewhere and have tea and come back*  
1221 *again, but I knew I wouldn't be able to do this long journey to Perth. So we phoned*  
1222 *up the holiday people and we rang them up and we got a letter from the doctors. We*  
1223 *rang them up and asked if we could postpone the journey to the September. And*  
1224 *that's what we did and when I went there I said to my husband, "I couldn't have done*  
1225 *this six months ago".*

1226  
1227 *M: And this support group sounds like an outing for you.*

1228

1229 B: Yeah it is. I enjoy the social things we do. They have little outings. I think we are  
1230 going on the 20<sup>th</sup> of June to a restaurant by the beach for afternoon tea.

1231  
1232 *M: When you're together what do you talk about?*

1233  
1234 B: Well they go around the group to see how each one is coping. Some women are  
1235 worse than others. I don't think I would have gone to a cancer support group if I had  
1236 of been much younger. I don't want to dwell on things; I have always been like this all  
1237 my life. The last time I went to the support group which was on the third of this month  
1238 it was rather morbid. But, I think that would put people off. I think it should be more  
1239 like a therapy to give people hope, to hearten people. I had already been over all that  
1240 and they know that. And I say look I was sixty-seven when I had all that done and my  
1241 attitude at the time was entirely different to the young people of today. When my  
1242 husband died in June 1988. My friend said to me, "You won't be on your own for  
1243 long". And I said, "Why shouldn't I be on my own for long". And I thought to myself I  
1244 couldn't present myself to another man and have to explain to him that I only have  
1245 one breast if he wanted to be sexually active. I wouldn't want to, I'd sooner not. But,  
1246 that's why I think it is more devastating for younger people. When I had my breast off,  
1247 I had two children and I had got over the menopause, so those problems didn't worry  
1248 me.

1249  
1250 *M: Finally when you reflect on your illness and when you think back over that time*  
1251 *what feelings come to mind.*

1252  
1253 B: The only thing I can remember is lying in bed and getting that post-operative  
1254 shock and ringing the buzzer and no nurse came. And I felt vulnerable. Like  
1255 everything else I sometimes think that some of the younger men, when their wives  
1256 have to have that done, need to be educated about it. Men need to be educated  
1257 about their relationships and how things change with one breast in terms of sexuality  
1258 and sexual relations.

1259  
1260 **Rosa**

1261 *M: Please tell me about your journey with breast cancer and how you found out*  
1262 *about it.*

1263  
1264 R: I was in bed one night and I had a real horrible dream. It was a real frightening  
1265 dream. I couldn't get back to sleep so I was tossing around a bit. I had decided then  
1266 that I would check my breasts and I felt this lump. My gut feeling was that it wasn't  
1267 good. The next day I went to see my doctor and saw a specialist that week. He had a  
1268 feel around and thought it was just a cyst. He did the needle aspiration and said that  
1269 the fluid looked odd. Anyway so they took this thing off too pathology and a couple of  
1270 days later I got a call from the doctor and was told that the lump was benign. And I  
1271 went to see him again and he rang a day later and said you have to come back. We  
1272 have done more pathology on the fluid and it has turned out not to be benign at all. It  
1273 was pretty awful...it was horrible. So I had a lumpectomy and I had it out and the  
1274 pathology showed there were a couple of small tumors around it and I had to have  
1275 another lot of surgery about a month later. So I had more breast tissue removed and  
1276 my lymph nodes removed. And so the lymph node situation was that thirteen nodes  
1277 had been removed and one was effected. I had a mastectomy and a reconstruction  
1278 at the same time. The reconstruction was complete by November 1998. And so the  
1279 whole time we were talking about chemotherapy and radiation. In the end I went in  
1280 there one day after the last lot of surgery I had and my doctor decided that a  
1281 hormone therapy would be sufficient for my treatment. So since then I have been on  
1282 Zolidex and it is a two-year course. I don't like these tablets because I haven't had a

1283 period and I can go into menopause. I get hot flushes and your skin gets really dry.  
1284 Your hair is thin. I was really pleased that I had avoided radiation and chemotherapy  
1285 and since then I have had two reoccurrences in that breast. I felt flat at the beginning  
1286 of the year and I felt myself starting to get a bit depressed and worried again. I called  
1287 the anti-cancer council and asked to be put on their phone service that they have got.  
1288 I ended up speaking to this woman Gill who had two reoccurrences like me. She has  
1289 been ok for six years so I look at people like Gill and I think I'll be all right and I really  
1290 do feel that I will be all right. I am very hopeful.

1291

1292 *M: Have you always had a good relationship with you parents?*

1293

1294 R: No I have always had a very strained relationship with my mother and you will find  
1295 that one cancer therapist's ex-wife actually attributes mother and daughter  
1296 relationships to breast cancer. But, my relationship with my mother was really  
1297 strained and after the diagnosis I mean my life changed in so many ways. I just had  
1298 to get rid of stuff and baggage that I had been carrying, you know emotional stuff. It  
1299 sounds a bit crass again but I had to do a whole lot of forgiving. Not that my mother  
1300 ever did anything to me. I think it was just your normal traditional Italian mother, but  
1301 we always did have a really strained relationship.

1302

1303 *M: Why did you feel like you had to forgive her?*

1304

1305 R: Well I had two other sisters and three brothers and I used to often feel like she  
1306 treated me really badly. I didn't feel especially loved by her. Isn't that awful? As a  
1307 child I can remember my mother being there for me when I was sick as a child and  
1308 her being besotted and worried. But, as an adult my feeling was that my mum was a  
1309 bit jealous of me. Then I got sick and you know you sort of re-evaluate your life and  
1310 the relationships that you have and all that sort of jazz. It became very clear to me  
1311 that I was very fortunate to have this big loving family and they are very loving and  
1312 my mother has just been there for me. You know they say that breast cancer, any  
1313 sort of cancer, is a really good thing. Sometimes it's the positive aspects that it brings  
1314 to one's life that makes you appreciate things. I feel so close to my mother now more  
1315 than ever. I rely on her and I don't feel there is any resentment.

1316

1317 Spiro, my husband, was supportive too in his own way. Spiro was completely freaked  
1318 out by it, but would never let anyone know that. He was there every time I went to the  
1319 specialist. He was there every time I had a mammogram so he was there with me the  
1320 whole time. He had to be strong and he had to be positive so that everyone else  
1321 would follow suit. It was a really difficult time. There were times in the middle of the  
1322 night when you're just lying there and you don't know if you're going to survive. I  
1323 used to have really horrible nights and I would just cry and cry. And everyone would  
1324 go to bed and I would be there at my mum's house in our bedroom and I would cry.  
1325 Spiro would wake up and it would just drive him insane because he could not handle  
1326 me crying and out of that came what seemed to be a real lack of sympathy. So I  
1327 didn't feel especially supported when I really needed it like in the midst of the night  
1328 when I felt darkness. And now I know that that is fear. My husband doesn't like it  
1329 when I meet up with the other women in the breast cancer support group. He never  
1330 overtly supports that. I am pretty sure that Spiro would rather I leave that. So  
1331 generally Spiro has been supportive, but I haven't felt completely supported by him  
1332 does that make sense?

1333

1334 *M: Did this put any strain on your marriage?*

1335

1336 R: Yeah absolutely. Spiro sort of felt that too. It did in terms of the lack of  
1337 understanding I used to feel in the middle of the night when I used to be terrified and  
1338 I used to beg him to hold me. But, you know again I just have to accept that that is  
1339 the person he is and I am convinced, I know that he loves me and that's what's  
1340 important. I haven't cried like that in a long time.

1341  
1342 *M: Can you please tell me about the breast cancer support group.*

1343  
1344 R: The breast cancer group is great. I am so disappointed that I didn't do this earlier.  
1345 I cope by looking at women like me. I go out for dinner once every six weeks with the  
1346 group and we sit around and we laugh. We are in a restaurant; we are not in a  
1347 hospital, or a cold clinical horrible place that constantly says you are sick you are  
1348 dying. It is so therapeutic being surrounded by women who are laughing, who are  
1349 just getting on with stuff doing really meaningful stuff, doing ordinary stuff. Before I  
1350 went to the group I did this transcendental meditation course which really is the thing  
1351 that get me back on track. So the meditation for me is important. It is a spiritual thing  
1352 and helps me to be spiritual within. During this time I was meditating twice a day and  
1353 I felt completely focused. I feel like I am not doing this alone, there has to be some  
1354 higher being here. Through meditating I feel I have become a bit more spiritual. I  
1355 stopped the meditation at the end of Jan when I found a lump in my scar and that  
1356 was when I hit rock bottom. I started feeling that terror again and it's not rational stuff  
1357 and that's what you feel. That's when I joined the group. But I know that talking isn't  
1358 enough. I have to get back into meditation so I have been trying to do meditation at  
1359 least twenty minutes once a day and I feel much better. I am quite busy at the  
1360 moment. I am struggling to find time for it, but I will I am absolutely determined. So I  
1361 will pick it up again and be consistent with it.

1362  
1363 *M: Growing up as a young lady, were you religious?*

1364  
1365 R: I was raised a Catholic. I went to a Catholic primary school and taught at a  
1366 Catholic girl's school. Right from the beginning of my appointment I actually said to  
1367 my principal, "Don't even think about ever giving me religious education classes I am  
1368 not interested". I never felt like I knew how to handle religion. I was such a cynic. I  
1369 had too many questions about God and whether he existed.

1370  
1371 *M: Has that changed? Are you still cynical?*

1372  
1373 R: No I can't be cynical. I felt that right from the beginning of my diagnosis.

1374  
1375 *M: Why?*

1376  
1377 R: The feeling of aloneness that takes place when you are told that you have cancer  
1378 is so horrible. The only way out of the darkness is to feel some kind of hope and I  
1379 have to trust that there is something more than physical stuff. You are trying to make  
1380 sense of what's happening to you. I look at some of the things that happened in my  
1381 life and I believe at some point there have been too many things that have happened  
1382 that may have been um like the opportunity to go down a more spiritual path. Those  
1383 paths were there but I resisted them. And then I ended up with breast cancer and  
1384 things changed. I still feel a bit embarrassed. I would love to go to church on a  
1385 Sunday because now when people speak in a spiritual way you're always very keen  
1386 and you listen harder. At the college I teach at there were a number of people who  
1387 had an impact on me and they were all real spiritual people. I used to say that I wish I  
1388 was like that. They were very peaceful and very centred. And I think I am getting  
1389 there, I must be getting there because I feel more peace today than I ever have.

1390 That's what the meditation does, it gives you a feeling of peace and trust and I am  
1391 open, I have to be open to whatever happens. It's had allowed me to be here. You  
1392 don't worry about stuff too much that isn't worth worrying about. I think meditation  
1393 has done that. I have stopped sort of questioning stuff too much.

1394  
1395 *M: In terms of illness?*

1396  
1397 R: I think for a long time I was unlovable. Liking myself all over again. I should have  
1398 had every reason to feel absolutely confident with who I was and I was never at ease  
1399 with who I was. I was independent within the marriage and I did what I wanted to do.  
1400 But I didn't really like myself. Nothing is black and white. I was doing all sorts of  
1401 things that were really good, but my self-esteem wasn't great. I used to project the  
1402 image of someone who was very confident and had it together. I don't think I ever  
1403 had it together, not that I have it together now, but I am a bit more at peace with it  
1404 now. Before the diagnosis our marriage was really strained. I thought he was having  
1405 an affair and he never admitted to it but I was pretty sure he was seeing someone.

1406  
1407 *M: So after you were diagnosed you had to forgive Spiro?*

1408  
1409 R: Yeah there was a whole lot of baggage with him as well.

1410  
1411 *M: So the major events that have taken place in your life and you have spoken about*  
1412 *coming to terms with a lot of baggage...are there any other major events or decisions*  
1413 *that you made during this period?*

1414  
1415 R: I don't know about events but I am certainly a bit more careful with my  
1416 relationships with people. I try to be good. I really try to restrain myself when it comes  
1417 to judging people. I try not to judge people. Before there were people who I spoke to  
1418 and people who I didn't necessarily speak to and that's not a nice way to live so I try  
1419 to be a little bit more loving and open in my relationships with people. I am really  
1420 conscious of what I say and I feel much easier about saying sorry. I don't know  
1421 whether it was just arrogance that stopped me from saying sorry. If Spiro and I have  
1422 a fight now once upon a time we would hold a grudge and wouldn't speak to each  
1423 other for days now it's not like that anymore. If we fight we may laugh after a couple  
1424 of hours. There are some subtle changes that have happened.

1425  
1426 *M: Was there a time in the last three weeks where you felt good about yourself?*

1427  
1428 R: Yeah I do have moments of confidence. I can come out here when it is raining. I  
1429 am just filled with awe. I never used to feel that way. I feel like I am full of love or  
1430 enlightenment. I come out here, sit here and have a cup of tea. It is so good to be  
1431 alive I never used to say that, I never used to say, "It's so good to be alive", when I  
1432 was well. You know I look up in the sky I feel that there has to be something more  
1433 than our physical life. Yeah I have moments like that all the time. When I meditate I  
1434 will get up before the kids and I feel like I am ready to conquer the world.

1435  
1436 *M: Please tell me about your body image.*

1437  
1438 R: I always felt like I was too fat and too short before the diagnosis. But, when I got  
1439 breast cancer I didn't give a hoot about what I looked like. I thought this is so  
1440 unimportant. Then I had the surgery and the mastectomy and issues of your whole  
1441 sort of sexuality, femininity, being a woman come to the forefront. You agonise and  
1442 feel depressed and you don't feel like a woman and you grieve over the loss of the  
1443 breast. After the mastectomy I couldn't look at a brochure without seeing a booby

1444 woman you know modelling lingerie or bras without wanting to puke because I felt so  
1445 sad. I used to love my breast and they are central to your whole being. It was very  
1446 difficult to begin with so I had a reconstruction and in a bra honestly you can't tell. So  
1447 the fact that I can wear clothes that I normally wear is a bonus. The fact that people  
1448 can't really tell that I have had a mastectomy makes life easier. I still have real issues  
1449 about the fact that I don't have a breast. I still feel incredibly saddened and every now  
1450 and then I think why me of all people? All that stuff you associate you know that  
1451 Catholic guilt shit. This is the punishment. But I have let go of a lot of that.

1452

1453 *M: You haven't really spoken about the role of your children in all of this*

1454

1455 R: Yeah because that is the hardest thing. Everyday I treasure being with my kids. I  
1456 try to enjoy everyday with my children...everyday is absolutely sacred. The thing that  
1457 causes me greatest grief is the whole prospect of not being here for them when they  
1458 grow up. I pray madly that I am here for them. My kids are absolutely besotted by me,  
1459 they love me like only a mother can really know so that's what makes me cry in the  
1460 end the whole thing about death. Death used to scare me a lot and it still does the  
1461 whole prospect of dying, but what scares me most is imagining their life without me  
1462 and that's why I had to do the stuff like meditation. I have every reason to get better. I  
1463 have to because I have these kids who I just adore and not speaking about them, I  
1464 haven't been avoiding them, but sometimes I just don't have the words to express  
1465 how I feel for them. We have so much going for us as a family. When I get really  
1466 upset I think about my children. All you really want as a mother is to protect your  
1467 children from things, from really unhappy sad scenarios. I want to protect them from  
1468 their mother dying of breast cancer. When you end up with breast cancer your whole  
1469 world just sort of collapses and you will do anything to bring it back to some kind of  
1470 normality. My kids are my main source of strength. I have them in my life and I have  
1471 to make the most of it.

1472

1473 *M: Were they a source of strength?*

1474

1475 R: Absolutely. When I was firstly diagnosed with breast cancer I would get into bed  
1476 with them and I would feel so assured. I used to feel safe with my son. I just don't  
1477 want to imagine anyone mothering my children except me. That's why I have to be  
1478 positive and believe that I am going to be all right. I am going to get through it  
1479 because I have every reason to believe that and the kids are the main reason and my  
1480 main reason for fighting. When you end up with breast cancer your whole world just  
1481 sort of collapses.

1482

1483 *M: Do you want to teach religious education now?*

1484

1485 R: I would love to teach religious education now. The only thing that would be  
1486 stopping me now is that I would become too emotional. When I go back full time I can  
1487 see myself asking for an R.E course.

1488

1489 *M: What about work colleagues? Were they very supportive?*

1490

1491 R: Yeah I had people come out of the woodwork...their prayers and stuff. People  
1492 used to ring me and say we are praying for you. I would hear that the staff would  
1493 have seminars and they would pray for me and I would feel very moved by that stuff.  
1494 And you know I wanted that. My mother goes to church all the time and she has this  
1495 prayer group on a Tuesday night. And her girlfriend would come around and put their  
1496 hands on me for a healing session and they would generate so much energy. And  
1497 that was my little initiation. And I would feel so much lighter until I got to the point

1498 where I would say to my mum, "Why don't you bring your friends?" Her friends did  
1499 the whole thing with the hands and healing and it restored my faith; they were so  
1500 loving. I have to believe because in the whole time I have experienced this I had met  
1501 people that have been absolute angels and I feel so privileged. When I was in the  
1502 hospital there were so many people that have come in my life because of the breast  
1503 cancer. They have been so inspirational and have really touched me. You can't help  
1504 but to want to give that back. I try to give it back by giving people a chance and being  
1505 open to everyone.

1506  
1507 **Rachel**

1508 *M: My first question is please tell me your journey with breast cancer. Begin with how*  
1509 *you came to find out about your illness.*

1510  
1511 R: It was August 16<sup>th</sup> 1999 when I got diagnosed with breast cancer. I found the lump  
1512 about two weeks before we were due to go on a holiday to Sydney. I came back from  
1513 Sydney and went to see my G.P who told me there was a lump. That day my doctor  
1514 told me that there is something serious in my breast. I was driving home from there  
1515 and my daughter was yapping her head off like she usually does and I am howling in  
1516 the car planning my funeral. I was wondering if I would ever see my kids grow up.  
1517 Cancer is all so unknown. When you first get diagnosed your life is like an emotional  
1518 roller coaster, like a merry-go-round. One minute you feel like you are doing o.k. with  
1519 chemo and the next day you feel like you have been hit by a truck and you are  
1520 waiting to get off the merry-go-round. I remember when I first told my mother of the  
1521 diagnosis. She fell apart and I told her not to cry because I wanted everyone to be  
1522 strong for my kids. Not mainly for me, but for my kids. I mean when you have kids  
1523 they always come first. I said to my husband as soon as I walked out of the hospital,  
1524 "You have to be strong no matter what happens, you have to be strong for our kids".

1525  
1526 *M: How did you find the doctors and all the medical staff in terms of the way they*  
1527 *dealt with you, the way they approached you?*

1528  
1529 R: My doctor was fantastic. I have been going to her for a long time. My surgeon who  
1530 did my mastectomy was tremendous. My oncologist is a male. I have nothing against  
1531 that but I really didn't feel one hundred percent comfortable with him. I felt that every  
1532 time I asked him a question I had to say, "I don't mean to ask a stupid question,  
1533 but...". I felt like I had to ask that just to justify why I wanted to know the information  
1534 and I don't know why he made me feel that way. I can't explain that.

1535  
1536 *M: Did it help having a mother and a sister who are nurses, especially a sister who is*  
1537 *an oncology nurse?*

1538  
1539 R: It was tremendous. I think the day after I got told my sister was at the anti-cancer  
1540 council getting information on breast cancer. She would come home with a thick  
1541 folder for me. She was a wealth of information.

1542  
1543 *M: And you have always had that closeness with your sister?*

1544  
1545 R: We are very close. My mum and dad separated when we were teenagers. Having  
1546 cancer has brought my sister and I much closer. She would go to the library and  
1547 borrow me books. And when I ended up in hospital she came in and told me  
1548 everything would be fine. The day I rang her on my mobile, when I was firstly  
1549 diagnosed, I walked in the door and she said, "We will help you!" She is my guardian  
1550 angel. She is younger. She comes around and takes my kids out while I am on  
1551 chemo and having a rough cycle, or she will come here and clean my house. I don't

1552 know how people cope by themselves who haven't got a family, or anything like that.  
1553 Yeah the whole family has been really good.

1554  
1555 *M: How do you cope with things?*

1556  
1557 R: Most of the times I have down days. I want to see my kids go to school and get  
1558 married. But I push that to the back of my mind. I am not going to dwell on that, I'll  
1559 take each day as it comes. And they said that they got it all and I have faith in what  
1560 they told me and I have done all the insurance stuff like chemo, radio therapy, but I  
1561 deal with it as best as I can. Some people don't talk about it. My daughter knows  
1562 what's going on.

1563  
1564 *M: So how did you tell your children that you had cancer?*

1565  
1566 R: Well my sister, who is a nurse, took my daughter to the children's hospital. My  
1567 daughter was taken to a ward with kids in it and she told her that these kids are sick  
1568 like mummy. This helped me to explain to her that I had bad cells and I had to have  
1569 special medicine and she had to help around the house a little bit. But, I think that  
1570 was the hardest day of my life.

1571  
1572 *M: Are there any major events that have taken place in your life since being*  
1573 *diagnosed with breast cancer?*

1574  
1575 R: When I got diagnosed I decided that I would baptise my daughter. She is going to  
1576 a Catholic school next year and I really wanted her to grow up knowing about God. I  
1577 think everyone needs something to believe in. Another event that happened was at  
1578 the start a friend of mind asked me whether I was going to ring my father and tell him  
1579 about my cancer. I haven't seen my father for many years. I came to also understand  
1580 why my mum did what she did and the choices she made. She did the best job she  
1581 could. They spilt up for a reason. You appreciate her choices a lot more. I decided I  
1582 didn't want to contact my father.

1583  
1584 *M: What do you do during times when you feel threatened?*

1585  
1586 R: Sometimes I sit around in self-pity and cry and use the expression that I have bad  
1587 hair days. But I will sit around in my pj's all day and not have a shower and feel really  
1588 sorry for myself. That's why I thank God for my kids because my daughter comes into  
1589 my bedroom every morning and says she loves me. That makes me think I have to  
1590 be bright and happy today because I don't want to walk around crying. I mean some  
1591 days my daughter says to me, "Why are you sad?" I know that I have to get better for  
1592 her. So I try to remain positive. Everyone says, "Oh you're just so positive". Like I  
1593 said from the start I wasn't going to let this thing beat me. They could inflict whatever  
1594 drugs they wanted into my body as long as I am around for my kids. I can live without  
1595 a boob and I can live without looking sexy at the pool. I have the love of my kids and  
1596 my husband and my family and that's all that matters. Two days ago my husband told  
1597 me he was scared I was going to die. He has had no one to talk to throughout all of  
1598 this. He told me that he didn't want to upset me but he said that some days it came to  
1599 a head where he was emotionally drained. And so he sat down and cried and said he  
1600 was scared of how to help our daughter cope with that situation and stuff like that.

1601  
1602 *M: What was your reaction to all of this?*

1603  
1604 R: I sat and cried and said, "Well I am not ready to die yet". And I have done all the  
1605 right things and there is not much I can say really. There is no one hundred percent

1606 guarantee in life is there. My husband has always been the very quiet type. He would  
1607 rather go for a run or a walk and stress out that way then actually talk to you and tell  
1608 you how he is feeling. I would rather yell and scream and get it out in the open and  
1609 then figure out what's going to happen. He just felt he couldn't say what he wanted to  
1610 say. There aren't a lot of support groups for partners because when I first got  
1611 diagnosed I looked into that and there wasn't anything available for him to go to  
1612 speak about how he was feeling about the situation. They're the ones that have to  
1613 carry this emotional baggage. Many women think they have to be macho and stuff  
1614 but they must be feeling a thousand emotions as well. My in-laws have been really  
1615 good. They minded my kids for out patient appointments. They have met me at the  
1616 hospital and taken the kids to the cafeteria if they have had to. It is good to have a  
1617 good family.

1618

1619 *M: Are there any issues you are struggling to deal with at the moment?*

1620

1621 R: Body image is an issue. I have never been well endowed anyway but what I had  
1622 was mine. I used to buy nice lingerie, Buying a nice bra and knickers, buying a nice  
1623 pair of bathers all went out the window. When you go for chemo you lose your hair  
1624 and stuff like that. One minute your trying to deal with losing a part of your body and  
1625 the next minute your losing your hair and your eyelashes and your eyebrows. My  
1626 fingernails and toenails fell off as well. By that stage your starting to think my God  
1627 what else will fall off? I am thinking once this is all over I will go and see my surgeon  
1628 and see about re-construction. I keep on telling people that I am going for the Pamela  
1629 Anderson look. I would like to buy a nice pair of bathers. My daughter started  
1630 swimming lessons. After the lessons she wants mummy to come in the pool with her  
1631 and have a play. Well bathers fail for people who have prosthesis. One week I just  
1632 wore shorts and a dark t-shirt but I just felt not comfortable doing that so now my  
1633 husband takes her because I don't feel comfortable doing that.

1634

1635 *M: What about with your husband do you feel comfortable with him?*

1636

1637 R: Not at the start no. We have never been ones to hide our bodies, but I wouldn't  
1638 get undressed with the light on. And then I spoke to him about it and said, "Do you  
1639 still look at me in the same way or do you look at me as if I am sort of a freak? Does  
1640 the scar disgust you if you do see it by chance?" He was really good about the whole  
1641 thing. He told me that he loved me for what was inside. I knew that but I needed to  
1642 hear it.

1643

1644 *M: Are there any other issues you are struggling to deal with?*

1645

1646 R: The fear of dying.

1647

1648 *M: Did you have that fear before cancer?*

1649

1650 R: No. I thought to myself, I'm thirty-four, I am invincible. I know that eventually we  
1651 will all die I can deal with that. I sometimes have dreams that I am at my own funeral.  
1652 When I wake up from that dream I know I am going to have a bad day. But, I think I  
1653 have to accept it that I may never get rid of the fear. I try to push it to the back of my  
1654 mind but I sometimes think about it a little bit.

1655

1656 *M: When you wake up in the morning are there certain things that enable you to gain  
1657 a sense of peacefulness?*

1658

1659 R: I love it when my daughter gives me a hug in the morning and she tells me that  
1660 she loves me. People being positive really help as well. I don't live having negative  
1661 people around me because I am o.k. and I will be o.k. and I need to be surrounded  
1662 by positive people. I am a pretty positive person anyway and I don't need people with  
1663 their morbid thoughts telling me the figures. I know the figures of how many people  
1664 die from breast cancer. I don't need to hear that from my friends. I don't need anyone  
1665 telling me that. I read the papers, I read all the stuff that anti-cancer council sends  
1666 me. If anything, cancer has taught me to value things a lot more. I don't stress about  
1667 silly things and I can't stand being around people who say, "Oh I feel shocking I have  
1668 a cold" because I think get over it. Go to the oncology ward and you know what it  
1669 means to be sick. I'd have a common cold any day compared to what I have been  
1670 through for the last year.

1671

1672 *M: Has there been a faith journey, or your spiritual journey throughout all of this? Did*  
1673 *cancer bring about a renewal of faith?*

1674

1675 R: Yeah my faith is stronger now. I pray every night before I go to bed, I pray that I  
1676 will get through this.

1677

1678 *M: Did you pray before?*

1679

1680 R: No. Now I pray I will be around for my kids...I'm going to cry. I pray that I'll be  
1681 around for my kids for a long time.

1682

1683 *M: So have you felt this sense of God more so now?*

1684

1685 R: I hope he is listening. I feel more connected to him now. I have written a journal for  
1686 my daughter. I wanted to say things to her that I couldn't say to her as a four-year-  
1687 old. When she is sixteen she can read it.

1688

1689 **Tamara.**

1690 *M: Please tell me about your journey with breast cancer.*

1691

1692 T: I was diagnosed in 1995. When I found the lump I thought it could be cancer. I  
1693 don't tend to dwell on things. When they told me it was cancer I was devastated. I  
1694 knew that my job would be a problem. I was working in the rag trade and was fairly  
1695 senior. I knew they wouldn't deal with it very well because it is male orientated and I  
1696 wanted to keep my job. I knew I had to tell them. I don't think at any point I thought I  
1697 was going to die quickly. I had read enough by that stage so that didn't worry me too  
1698 much. I have lived an independent life and I am by nature a fairly aggressively  
1699 determined person so when I was diagnosed I didn't have any regrets about what I  
1700 had or hadn't done. I did however have problems with work once I told them about  
1701 my situation. When I was in hospital the social worker was quite good and I knew that  
1702 if someone was going to give me a hard time I could ring her. The social worker knew  
1703 all the legal ramifications which was necessary when I was treated badly by work.  
1704 Not that she actually did a lot, but I knew she was there.

1705

1706 *M: Were there any other people who helped you to cope with your illness?*

1707

1708 T: My boyfriend at the time was really good. I got sick and he came down and looked  
1709 after me. He is now my husband and has been wonderful.

1710

1711 *M: How did you feel in terms of body image and sexuality?*

1712

1713 T: It wasn't really an issue. I have always thought the best part of me is my brain  
1714 although I am reasonably pretty. If it was a brain tumor I would have been  
1715 devastated, that would have been really traumatic. My brain and my personality I  
1716 know are much more important than that. I was lucky. I could handle it if my hair fell  
1717 out. I am in the rag trade so I can fake most things. The hair falling out becomes  
1718 much more of an issue for other people around you. If you lose your hair it tells other  
1719 people that you are sick and they may then interact with you in a different way. The  
1720 hardest thing for me is that the chemo and the radiotherapy have slowed down my  
1721 metabolism and it is quick in the aging process. Menopause didn't come on at all and  
1722 I was really lucky.

1723  
1724 *M: Please tell me about your work incident.*

1725  
1726 T: Once I told my boss about my cancer, he virtually tried to push me out. I thought  
1727 bugger this I am going to do something about it and I took him to the equal  
1728 opportunity commission. I won, but it was all so stressful. When I was firstly  
1729 diagnosed I knew that I wanted to get back to work and know I could still do it. There  
1730 is a physical element of my job. My job includes cutting fabric and lifting fabric and  
1731 there is then the mental side. I didn't want to go back for a long time, just six months  
1732 and they didn't want that. One day my boss called me into his office and said to me,  
1733 "You know your going to die. My father is a doctor and you will die". These are the  
1734 kind of people you don't want to be around. They want you to go away and  
1735 disappear. Probably to this day they can't believe I am still here. I think that was the  
1736 other thing I had to get out of that mind set. As an employer you shouldn't do that.  
1737 You are there to encourage people and if they want to leave they leave and if they  
1738 want to stay they stay. It was so funny. They tried to make it economical. During the  
1739 hearing, the arbitrator said to my boss, "You can't do that. Do you want me to read  
1740 the section to you I know it fairly well. You are not allowed to do that". After this I  
1741 stayed for a few months then moved to teaching. I guess the worst thing that has  
1742 happened to me now is that I cry too much. I cry more now than ever before. I don't  
1743 have a problem with showing my emotions it's just I don't want to be sad. Too much  
1744 makes me sad. I am more concerned that this sadness is doing something in my  
1745 head and I am worried about the knock on effect. Especially when you have  
1746 something like breast cancer. Breast cancer happens to people who are very good at  
1747 controlling things. It happens to women who you think of all the people it shouldn't  
1748 happen to her. Out of all of my friends I was probably the fittest and the strongest and  
1749 the healthiest. I never get colds, never get any of that and that is because I was so  
1750 good at controlling my body and the things around me.

1751  
1752 *M: Please tell me a bit about your photographs because they sound really interesting.*

1753  
1754 T: I took some photos before I went into hospital and that was to get a shot of the  
1755 boob before it was cut off. That's how it started and I just kept on taking photos after  
1756 that. I took photos the day of the surgery and the next day after. I felt pretty good the  
1757 next day. I don't look at these photos too much. It is good though because you don't  
1758 have to worry about remembering. These photos are good for other people as the  
1759 fear is probably the worst thing. When I first was told about my mastectomy I thought  
1760 well what is this going to look like. When you are in the trauma of being told, your  
1761 memory is bad, but your visual image is better. I didn't have any visuals to look at.  
1762 Having taken these photos I am able to help others. Now they use these photos all  
1763 the time at the hospital because I have given them a set. I will do something with  
1764 these eventually, perhaps putting them in a book just so people can see a visual  
1765 image of people who go through it.  
1766

1767 *M: Were there any other major events that took place once you were diagnosed with*  
1768 *breast cancer?*  
1769

1770 T: I got married. I tend to not work so hard. I moved to the country, but that was more  
1771 a move of convenience. I knew that would be good for me. I don't tend to worry as  
1772 much about things. I tend to if I am tired to have a sleep. You learn to do that when  
1773 you have chemo. If I am here and I am doing something and I am tired in the  
1774 afternoon I might lie down for ten minutes. In the past I would never have done that, I  
1775 would have kept on working. There is also the age factor with cancer. Sometimes I  
1776 think the chemo has made me aged. I have put on a lot of weight and that has been  
1777 difficult to get off. It annoys me not being as fit, knowing that you have to try harder to  
1778 lose weight. But friends say that that is what happens in your late thirties. Your  
1779 chemo influences your metabolism. I didn't get menopause, which was good. Like  
1780 now I have had two miscarriages and it could be the chemo I suspect but no one  
1781 would know.  
1782

1783 Another thing was that my mother was a problem when I was sick and I will never  
1784 forgive her for it. She came down when I got the diagnosis on that day and when I  
1785 was in hospital. In hospital she would not listen to what my husband was telling her  
1786 about my illness. My mother went and put herself in another room and then my  
1787 friends at hospital had to look after my mother. She had got herself so worked up  
1788 about it. My friend said I found your mother in a foetal position. My friend ended up  
1789 looking after her and taking her home. I got angry that she got upset. She was really  
1790 concerned about how she was going to deal with a sick daughter than the fact that I  
1791 was sick. I have never been able to rely on my parents emotionally. They will never  
1792 be an emotional support. That is probably why we are all independent. It is my  
1793 friends that are my emotional support.  
1794

1795 *M: What do you do during times you feel threatened or in pain?*  
1796

1797 T: I stand my ground, I read up on everything. I have a high tolerance for pain. I  
1798 meditate. I generally do it either in the morning or at night. I feel like I am in control. I  
1799 use a few different techniques. One is I concentrate on a white light. I used to  
1800 meditate when I was little. I learnt to do it again. I have to be doing something and  
1801 that makes me feel good. Housework, painting...  
1802

1803 *M: How is it when you wake up in the morning?*  
1804

1805 T: I can go days without remembering that I had cancer. I mean I know I have had  
1806 cancer but I don't see it as that big ugly thing that other people see it as I suppose. I  
1807 am the most likely person to make me better. I take on this responsibility. Others can  
1808 help, but in the end it is up to me. I am trying to use this experience to become more  
1809 focused, less stressed, more in control and more relaxed about what I can and can't  
1810 do. I don't have a faith. I would say though that if I got really sick again I would  
1811 become more religious, but I would use it in a sort of meditative way. I don't think  
1812 there is a lot of difference between meditating and lying still and relying on God. They  
1813 are both the same. Religion is only when you put a set of rules and images  
1814 developed through a culture on a same plane.  
1815

1816 *M: What about support groups?*  
1817

1818 T: Yes I attend one support group. What I have noticed though is that different people  
1819 get really focused on things and lose their balance. Some people's way of dealing  
1820 with it is to blame the medical profession and they will focus on getting them back.

1821 The best person to know if you are sick is yourself. The best person to find a lump is  
1822 you. And if you are not happy with a diagnosis then go and see another doctor. If  
1823 there is a pain I am good at knowing where it is and trying to gauge whether it is  
1824 serious. So I am in tune with my body. During times when I am in pain, I see God as  
1825 something that I can draw on to give me strength. I think there is some power out  
1826 there that we can all use.

1827

1828 **Debra.**

1829 *M: Please tell me how you found out about your cancer. How did you feel at the*  
1830 *time?*

1831

1832 D: I was on holiday in Queensland in September 1996. I found a lump in my breast. It  
1833 was about the size of a ten-cent piece. I had always examined myself because my  
1834 mum's sister died of breast cancer. I had been going to the gym a lot. I also thought I  
1835 had developed some muscle damage. I saw my G.P who said it was just a lumpy  
1836 breast. In February the next year I went to see another doctor because I had a rash  
1837 on my hand. I thought while I am at the doctors I will get him to inspect the lump. I sat  
1838 down and she kept feeling my breast and it hit me. She told me that I needed to get it  
1839 checked out. I had a mammogram and an ultra sound. I came home and read the  
1840 report and it said 'malignant mass'. I was thirty-five when I found the lump. The  
1841 cancer was quite big and they had to take my whole breast off. Losing my breast  
1842 didn't worry me at all. I felt like I had an alien growing in me and I wanted it out. That  
1843 is exactly how it felt. Like an alien had taken over my body and I could feel it trying to  
1844 grow through me and I just wanted it off. I didn't care. So I told the doctor to take it  
1845 off. I like to wear sexy clothes to the gym and I knew I would have to wear different  
1846 clothes so people couldn't see I only had one boob. I agreed to have a tissue  
1847 expander put in. I worried about what it would look like. Since having the operation I  
1848 don't have a nipple and I have a big scar but when I have clothes on you can't tell.  
1849 And I feel quite comfortable that no-one is looking at me in a funny way; when I go  
1850 out I feel comfortable. I think that was important for me.

1851

1852 *M: How was your boyfriend?*

1853

1854 D: He was fine. I wasn't changing as a person. Sexuality wise I don't have a problem  
1855 with that. Even if I had to have both of my breasts cut off it would be o.k. I know a lot  
1856 of women see it as a sexuality problem. I call this my rock.

1857

1858 *M: Have there been any major events since you have been first diagnosed?*

1859

1860 D: I was very sick on chemo and had a lot of side effects. I was so fit before and in  
1861 losing this fitness I suffered from depression because I couldn't walk around the  
1862 supermarket or run six kilometers. I read about a group of women who did  
1863 adventures for women with breast cancer. They would do a range of activities. So I  
1864 did a paddle along the Murray River with them. It was one-thousand kilometer  
1865 paddle. That took me five weeks. I dealt with a lot of emotions. I finished chemo in  
1866 September and had my implants in November and I started paddling at the beginning  
1867 of March. I didn't have a lot of time in between to come to terms with my illness. So  
1868 while I was on the river I went through a lot of emotions. Anger was one. I was very  
1869 angry that I needed to prove to myself I could get fit. I was angry that I was away  
1870 from my family and I had to prove things to myself. I cried a lot, I cried a lot while I  
1871 was paddling; I was so tired. The fact that I was in pain whilst paddling made me cry.  
1872 This made me angry because if I didn't have breast cancer I wouldn't have pain and  
1873 this added to my sadness. While I was away Linda Mc Cartney died. When we came  
1874 back from the paddle a woman who paddled with us died three weeks later. Then six

1875 months later another lady died and we knew at the time when we all together you  
1876 were thinking who is going first and that was hard. The hardest part is losing a lot of  
1877 really good friends, a lot of them die. Some people might have a good prognosis and  
1878 die and you wonder why, why them not me? My cancer was aggressive.

1879  
1880 *M: How did you feel walking for 'Relay for Life'?*

1881  
1882 D: Walking the survivor's lap was very emotional. I tried to explain it to some of the  
1883 women at the support group how I felt. And a lot of those people there have had all  
1884 sorts of cancer. It is great that when you are on the track you wear pink sashes. Pink  
1885 sashes identify who the survivors are. You really feel a bond with them, those people  
1886 walking around the track with no hair. I always think of the people who are not there. I  
1887 quite often talk to my friends in my head. I really enjoy being involved in it all. I  
1888 always cry at these events. I am not a really soft person, but I cry for the people I  
1889 have known, their kids, their partners, what they have left behind. When we have our  
1890 meetings, we all hug and kiss. You know what they are feeling and where they are  
1891 going and what their fears are. And trying to explain it to someone else is different.

1892  
1893 I went to an aerobic course and there was an instructor there and she had cancer.  
1894 Anyway she walked up to someone and said, "If I put a gun to your head right now  
1895 what would be going through your mind?" And people were saying, "Oh I would be  
1896 scared, I would cry" and all sorts of things. She didn't like the responses she was  
1897 hearing and then I said, "What's going through your head is that you just want to be  
1898 here, you are just happy to be there that second". She liked this response and I told  
1899 her that she couldn't expect people to know that; she had felt it but they hadn't. You  
1900 will talk to people and they will say she is still fighting and she is so sick, why doesn't  
1901 she just give into it. I will say you can't give in. There is just something in you, you  
1902 just want to be around. I never thought about these kinds of things before breast  
1903 cancer. Mother's day service at school kills me because I might not be here next  
1904 mother's day. When my eldest daughter did her confirmation that killed me because I  
1905 may not be around to see my youngest daughter do hers. Things like that kill me. It is  
1906 really hard because I will sit there and I will cry and I wonder what others might think.  
1907 All those things...it does get easier but you still wonder.

1908  
1909 *M: Are there any unresolved issues?*

1910  
1911 D: I suppose one of them was my father. I never had a good relationship with my  
1912 father and he left me when I was five and I found him when I was sixteen. When I got  
1913 sick I rang him to tell him I had breast cancer. I have never heard from him since. On  
1914 and off I have often thought I should let him go rather than keep a relationship with  
1915 him. I haven't spoken to him for four years. I became a little more selfish. I don't have  
1916 to make excuses for making time for myself. When you have kids it is very hard to be  
1917 selfish, you tend to feel guilty. I know how sick I can be on chemo. If I get sick again I  
1918 will not have the luxury to do what I want. I deserve to do things for myself, that's  
1919 what I say.

1920  
1921 *M: Are there any issues you are struggling to deal with?*

1922  
1923 D: The relationship I was having with that guy when I was sick ended eventually. We  
1924 got through the chemo, but he thought I would go back to being normal again. Things  
1925 never go back to normal once you have been diagnosed with cancer. I got very  
1926 involved with support groups, paddling, relays and conferences. He didn't like that.  
1927 He wanted us to go back to being just us, very close. I met another guy now who I  
1928 am engaged to but I am not very sure about this either. His mother died of breast

1929 cancer three months before I met him. He is really great because he is really  
1930 supportive of things I want to do. Having had cancer makes you appreciate life more.  
1931 I see the next ten years as the best ten years of my life. At the moment I feel I can do  
1932 anything I want. I own my own home I can work, I feel well. I had trouble with  
1933 hormones after chemo and I went into menopause. Now I am finally feeling I can do  
1934 everything I could do before. Now I am thinking I have the next ten years and I want  
1935 to be really selfish, but if I marry him I have to consider his feelings and what he  
1936 wants. I don't want to do that. I want to do what I want to do. Your life definitely  
1937 changes when you get cancer, the way you look at things. Things are more precious,  
1938 there is more you want to do and experience and you become more selfish. I feel like  
1939 this is my life, whatever I have left this is mine. Apart from the kids, this is my life.

1940

1941 *M: When you reflect on your illness, what feelings come to mind?*

1942

1943 D: In a lot of ways I am glad I had cancer. I don't think cancer necessarily changes  
1944 your life for the worst. I think you get a lot out of it, you learn a lot about yourself, you  
1945 learn to appreciate life a lot more. I feel lucky in a lot of ways. I can sit in a backyard  
1946 and watch the birds, in the sunshine and I am so happy. I take pictures of magpies  
1947 on the front lawn. The kids come home and they think I am off my tree. Things like  
1948 that make me so happy because I can feel it more than other people and I would  
1949 never have had those feelings if I didn't have breast cancer. Even my wedding day  
1950 that was great, but the feeling of watching the magpies, that's different. Everything is  
1951 heightened. When I first got married we had to own our own house. We had to have  
1952 a boat and a caravan and a car. We had all that and it was really important and now  
1953 it is not. Materials aren't important. I don't have to have a flash car and a new lounge  
1954 suite. Other things make me happy. It is not all bad having cancer.

1955

1956 *M: Were there any morning resources that you relied upon for peace?*

1957

1958 D: When I was going through cancer that was really hard. You know what kept me  
1959 going, the kids. I had to get up, get their breakfast, and take them to school. I wanted  
1960 to be there for them in case I died. I wanted them have to those memories of me, of  
1961 mum making me breakfast and of mum driving me to school. I didn't have a lot of  
1962 energy to do stuff. Because I never had a father that was hard as a child. I knew how  
1963 hard it was not having a father and I knew how horrific it would be not having a  
1964 mother and I didn't want to do that to them. I wanted them to have their mother and I  
1965 would have fought to be with them, taken any drugs even if I would only have been  
1966 around for another six months. All this was very important.

1967

1968 *M: Has there been a faith journey throughout this?*

1969

1970 D: I don't know if it helped me. I believe everything happens for a reason. I believe I  
1971 got cancer for a reason. I didn't know what that reason was at the time but I knew  
1972 there was a reason. Now I know. I am very involved with a breast cancer support  
1973 group for women under forty-five, which is very important because I had no support  
1974 at all through chemo. My surgeon gave me my chemo, which meant I had no contact  
1975 with others going through chemo. So I went through twelve months of hell on my own  
1976 without being able to say to someone else, "Do you feel like this? Have you  
1977 encountered these emotions? Are you worried about this?" Another reason I feel that  
1978 I got breast cancer was that someone was knocking me on the head to tell me to  
1979 wake up and enjoy what I had. I have always been a workaholic all that sort of stuff.

1980

1981 I tell my story if people want to know. Friends my age aren't going through  
1982 menopause so I can't really talk to them about hot flushes and sweats and feeling

1983 like your fifty as they don't really understand. Once I joined a support group I was  
1984 ringing a lot of people who could understand. Listening to other people makes me  
1985 feel good, especially when I am able to help others. But, I also feel that these people  
1986 will be there if there is a reoccurrence and that is peace of mind. Another support  
1987 group I go to has women with advanced breast cancer who are dying. You leave  
1988 there feeling so lucky that you are not in that situation but you also know that if you  
1989 ever get to that stage they will be there for you and that is very comforting.

1990

1991

*M: Was there a kind of higher source in your life during your illness?*

1992

1993

D: I think you have to get yourself through for whatever reason. I did pray. I am more  
1994 religious now than before, but I am still not very religious. I did pray when I went to  
1995 church and felt someone was listening to me. I really think I would become more  
1996 religious if it came back. I don't know why, I can't explain it but I found more of a  
1997 need to go to church when I was sick. Whether it was just a peacefulness when I was  
1998 at church I don't know. Maybe it is a hope, maybe it is something to cling to and if I  
1999 am going to die. I need to have something to help me through it to think well I am  
2000 going there and I will be fine. Maybe that's what it is maybe you need something to  
2001 hold on to.

2002

2003

**Grace**

2004

*M: My first question is can you please tell me how you came to find out about your  
2005 breast cancer.*

2006

2007

G: It was a Friday night in 1998 and I was doing my Yoga exercise and somehow I  
2008 stretched and I felt a lump. I went to my local doctor and I had an ultra sound. The  
2009 specialist was fairly confident thinking it was a fibroid and he told me to see him the  
2010 following week to get the results. He seemed positive. I get there and he told me the  
2011 fluid was o.k., but they found some cells on the needle. He said not to worry, as he  
2012 had to take out the lump to have a look at it. Eventually I went to hospital and the  
2013 nurse told me that I had been booked for an overnight stay. The surgeon came in  
2014 and he told me that a fist full of meat would be taken from my breast. I woke up from  
2015 surgery and found out that they had taken my lymph glands out. A calmness came  
2016 over me and I was o.k., I felt happy. The doctor phoned me the following Wednesday  
2017 and said, "I would like to see you tomorrow, it is cancer and I would like to speak to  
2018 you about it". The doctor was very supportive and explained everything. He said to  
2019 me, "We got the cancer in time and no further treatment is necessary". I felt good,  
2020 the doctors were supportive. Then my husband and I got books and read up about it  
2021 and we found this good book about my breast care and I learnt my cancer wasn't  
2022 threatening. The book said that radiotherapy would not be threatening in my case so  
2023 I decided against it.

2024

2025

Two weeks later I told the oncologist that I wasn't prepared to have radiotherapy. I  
2026 found him quite negative and decided not to go back to him. A lot of people play on  
2027 your emotions. I spoke to my yoga teacher and he said, "If it wasn't for me starting  
2028 the yoga eight months ago I would have taken it harder". When I had my fibroid taken  
2029 out a year before I had begun yoga. They had to hold me down on the trolley I was  
2030 shaking so much. But, a year later when I was faced with the operation for breast  
2031 cancer, I was fine. My inner voice kept telling me after my diagnosis with breast  
2032 cancer that you have to eat well so we ate well and I started taking my vitamins  
2033 straight away. I felt such a sense of well-being. It was like something had been  
2034 removed and that energy could start flowing. Actually when I went to Yoga and when  
2035 they spoke about God I got angry. I didn't want to hear the word or say it. I thought if  
2036 there was a God my life would have been different. This word is a sick word. If there

2037 was a God these things wouldn't have happened. Then you go to Raj Yoga and you  
2038 learn about God and how to approach life, how everything works. God is not there to  
2039 fix your life, you should take responsibility for your own life. I was blaming everyone.  
2040 Yoga taught me control and self-discipline. These skills helped me with my problems  
2041 in the past. I am now peaceful. We do a lot of meditation at the centre, we do a lot of  
2042 healing and forgiving. You mentally picture the person from a view and whatever  
2043 emotions you have towards them you let them go. They teach us about the virtues  
2044 within, anger, jealousy, they teach you how to let these destructive emotions go. You  
2045 learn so much about yourself and you look at life differently.

2046  
2047 I started tai chi six months ago. I meditate twice a day. I look forward to this and the  
2048 people I have met. People can look at me and see me as a victim because I had  
2049 breast cancer. I am not a victim, I am proud of it and I am pleased I went through it. It  
2050 has been a beautiful experience and people look at me and say how can it have  
2051 been a beautiful experience. It has been wonderful because it has brought me closer  
2052 to God; cancer forced me to cope with my fears. Cancer has been positive. And  
2053 another thing, when they take the bandages off your breast doesn't look nice. What I  
2054 have done is I have given special love to that breast saying, "I love you, it doesn't  
2055 matter what you look like". I keep talking to my breast like a child saying, "You will get  
2056 all the attention now".

2057  
2058 *M: When you think back on your illness what emotions come to mind?*

2059  
2060 G: Happiness comes to mind when I think about my time with breast cancer. There is  
2061 no sadness, there is no grieving, no anger. Breast cancer was just a beautiful  
2062 experience. I found God in me for the first time for those three weeks. Even my  
2063 mother said there is something about you. She noticed the change but she couldn't  
2064 understand. I have learnt acceptance. I accept my breast, I accept my past. I showed  
2065 the scar to my mum and she said, "Oh that doesn't look too good". I didn't mind she  
2066 was the one with the problem, not me.

2067  
2068 *M: What about your son? How did he deal with your illness?*

2069  
2070 G: He was a mess and he didn't feel comfortable coming to hospital. But, we talked  
2071 about it, he listens, but to a point. I went back to Germany after my diagnosis. When  
2072 I came back I told him that I had been sexually abused. He didn't know previous to  
2073 that. He was angry and so sad that he saw a counsellor the next day at work. The  
2074 counsellor said, "Your mum is not a victim, she is a survivor". Families have a way of  
2075 telling stories and cancer brought my story forward. Before I had cancer I was so  
2076 materialistic, I was an empty shell and I was so unhappy. Now I have to drag myself  
2077 to go shopping. Now I feel I give more without expecting something back in return.  
2078 My husband mentioned that breast cancer had brought us closer. Even today my  
2079 husband will talk about it. My doctor said to massage my breast every night and after  
2080 three months I said to my husband, "I can't be bothered". Now he massages it for me  
2081 and that is really nice.

2082  
2083 *M: Have there been major changes in your life since breast cancer?*

2084  
2085 G: I was brought up a Catholic. Church at the time didn't give me anything. Then  
2086 early in my teenage years I stopped believing. Then at forty-six I was diagnosed with  
2087 breast cancer and there is a renewal of faith. I believe it I hadn't of had cancer I  
2088 wouldn't have found God, found inner peace. I do meditation, yoga and tai chi. If this  
2089 is done properly you get a lot of energy through your body. Like your shakras open  
2090 up. You have seven. When they are all harmonised you are healthy, you feel alive.

2091

2092 Food. Another big thing is that my husband and I have become vegetarian. When I  
2093 started Raj Yoga, within six months I became a vegetarian. You meditate and your  
2094 body says to you I don't want meat any more. Meat is animal fat and because the  
2095 animal has been killed, the energy stays in the animal and the bad karma enters into  
2096 you once you eat the meat. I don't miss eating meat. My husband turned vegetarian  
2097 a week after me. My son still eats meat. I don't like the smell, meat smells like  
2098 something has died. Spirituality is not about the psychological side of things, but also  
2099 about the nutritional side. The food I eat is now very important in my life. We also  
2100 don't eat onions and garlic. I now eat a lot of soya products. It is a gradual process. I  
2101 am happy with cooking. I used to hate lentils. Now I can eat them.

2102

2103 **Kay**

2104 K: I have had mammograms since I was fifty. I had this one mammogram and they  
2105 asked me to come back for another one. With me what they discovered the second  
2106 time there were these white dots around it. They eventually cut these white dots out.  
2107 It was a day procedure at the hospital. I had a general anesthetic and they cut six  
2108 inches long across the breast and supposedly got it all out. And I went back about  
2109 ten days later and they took the stitches out. I had to have a mammogram again and  
2110 they asked me to go on this trial. They told me to do nothing I felt like a guinea pig. I  
2111 was going back every three months and they would feel me for lumps. Twelve  
2112 months later they did another mammogram and they found another mass, but this  
2113 time in a different area. They cut it out and once again I had to have another  
2114 mammogram.

2115

2116 *M: Did you feel leading up to it that the medical staff had been quite negligent?*

2117

2118 K: I felt they were quite negligent. For twelve months I had nothing done for me. I  
2119 was very upset. Anyway eventually I had to go to Wollongong hospital to get the  
2120 stitches out. The doctor came in and said, "It's not good news. Your breast is full of  
2121 cancer and we are going to have to take it off". At that stage it didn't seem to worry  
2122 me. I wasn't really perturbed I don't know why. Anyway eleven months went by and I  
2123 started getting very upset about everything. Every time I looked at a magazine or on  
2124 television there was something to do about breast cancer. I was crying all the time. I  
2125 could not stop myself crying. I phoned up my breast liaison nurse and as soon as she  
2126 answered the phone I burst out crying. She asked me whether I was crying and I said  
2127 yes. She said, "Thank-God we have waited all this time for you to have a reaction  
2128 and there has been no reaction". Because my breast was gone and all of a sudden I  
2129 couldn't look at myself. I felt ugly and I just couldn't look at myself.

2130

2131 I have a gentleman friend and he has never seen me naked, I just couldn't let him.  
2132 He has touched me there which made me feel really good that it doesn't upset him.  
2133 He is wonderful. I have been with him for two years. Anyway this nurse sent me to  
2134 four different groups. I felt that the breast cancer group would be the best group to  
2135 contact. But I am the only one there that had a mastectomy and the others have had  
2136 lumpectomies but they have never had their breasts removed. In fact I had contacted  
2137 the hospital to say that I wanted the right one off too. I said this because I am  
2138 concerned I will get it in the right one as well.

2139

2140 *M: So were there any other aspects associated with body image?*

2141

2142 K: I had chemo for six months and I was fortunate not to feel nauseated, but I was  
2143 extremely tired all the time. I lost my hair, which grew back curly instead of straight.  
2144 Now my curls have gone. I felt good about my hair and I said that was the one good

2145 thing about having cancer was that I finally had hair that I wanted. And I said that the  
2146 only other thing is everyone I know who has had cancer loses weight, I put it on. I  
2147 wasn't nauseous with it but when I first started I was tired for a couple of days after  
2148 about two months; it would take me weeks to get over it. I was just exhausted. It was  
2149 so hard just to put one foot in front of the other.

2150  
2151 *M: Have you resolved certain aspects in your life since being diagnosed?*  
2152

2153 K: I didn't think much of dying before I had cancer. I have since put all my personal  
2154 affairs in order and I have spoken to my son about funeral arrangements. I have also  
2155 registered as an organ donor. I also told my sons that I wanted to be cremated and I  
2156 want my ashes thrown where my father's and mother's ashes were thrown.

2157  
2158 *M: You mentioned about body image and you said that recently your partner touched*  
2159 *you and you felt good.*  
2160

2161 K: Yeah it took a while for me to allow him to touch me. We were going for about ten  
2162 months before we became physical. I have been divorced for about seventeen years  
2163 and I hadn't even held hands with anyone in that time until I met Tim. So it was pretty  
2164 hard but he is so good. Since November I have been crook for four months. He slept  
2165 over a few times over the last month or so and we just have gone to sleep holding  
2166 hands. He said, "I know you're not in a situation to go anywhere further, but this is  
2167 good enough for me". I can't think when it was that he touched me and I started  
2168 crying. He asked me, "Why are you crying?" I told him that I was shocked he did that.  
2169 He said, "It feels lovely don't be silly". He is a very nice man.

2170  
2171 *M: When you feel threatened or in pain what do you do?*  
2172

2173 K: When I feel threatened or in pain I cry a lot. I am a very tearful person. It has  
2174 probably been worse since I had the cancer because I am now in a lot of pain. I am  
2175 now on oxygen. I don't cry in front of people, I cry a lot by myself. I go to a  
2176 psychologist and I have been going to her for eight and a half years. For so many  
2177 years I would never cry in front of my psychologist. I think it was the cancer that  
2178 trigged it off. I have had a rotten life. I was sexually abused from the age of ten to  
2179 thirteen. I also had a very violent marriage. For twenty-three years my husband used  
2180 to belt me once a week. I had a wonderful job as a legal secretary and I was just  
2181 getting on my feet after my divorce when I was diagnosed with cancer. I cannot  
2182 believe that so much has happened to one person. And when I was in hospital  
2183 recently, I told them my life and they couldn't believe me. I have had eight  
2184 miscarriages. I have had a rotten life. Cancer has been the catalyst. It is as though  
2185 God is saying, "Well she is getting by with everything else, let's give her something  
2186 else to give her problems". But you know I have always prayed to God every night. I  
2187 never prayed to God for anything to do with me. I don't mention my cancer at all.

2188  
2189 *M: But in terms of spirituality do you feel anything as a result of cancer?*  
2190

2191 K: The only thing I feel is that God is looking down on me and saying, "She has put  
2192 up with that let's see how much we can throw at her".

2193  
2194 *M: So you're saying cancer has been more of a test. Do you feel like cancer is more*  
2195 *like a punishment at times?*  
2196

2197 K: Well my psychologist said that I supposedly blame my self for having a rotten  
2198 marriage and so many miscarriages. She also said that I believe I deserved the

2199 beltings I got off my ex-husband. When the psychologist said it I thought it made  
2200 sense because I was sort of blaming myself for what happened as a youngster. But  
2201 now I realise that it wasn't my fault. I discovered this when I was forty-nine.  
2202

2203 *M: I have just noticed your Indian statue there and your dream catcher. Can you talk*  
2204 *a little bit about that? What is the significance of Indians in your life?*  
2205

2206 K: When I went over to America about five years ago an Indian chief gave me a  
2207 stone and it is supposed be a healing stone. He actually gave it to me when he saw  
2208 how I was. When I came home I had it made into a necklace.  
2209

2210 *M: Did this Indian man say anything to you, did he impart any words of wisdom upon*  
2211 *you?*  
2212

2213 K: Yeah. He said that if I wear this stone it will help to take away the pain. And I have  
2214 actually only taken it off a couple of days ago because it was hurting me in the night.  
2215 But, since then I started becoming very interested in the American Indians.  
2216

2217 *M: When you get up in the morning is there anything that allows you to feel a sense*  
2218 *of peace or calm?*  
2219

2220 K: No I hate the morning to be honest, isn't that terrible! This has been coming on  
2221 gradually. I can't be bothered doing anything because any time I try to do something I  
2222 end up flattening myself because I do too much. I just don't have the energy to do  
2223 what I want to do. My boyfriend is so fit. He is always in the is garden and he runs  
2224 messages for this person and that person and I lie there and I think I wish I could get  
2225 up and do all that. Like my son Jim who has been an absolute wonder for me. My  
2226 other son is too scared to be around me too much. He hardly ever visits me in  
2227 hospital and hardly ever phones me in hospital.  
2228

2229 *M Are there any sources that make you feel better?*  
2230

2231 K: I sew and that makes me feel good and a bit active. I just love being able to sew.  
2232 See I can sew and sew and I will look at the time and five hours have passed. I get  
2233 out to my sewing club once a week. We have a 'chin wag' and it is like a social event.  
2234 One of the girls was away for three months and she came back and she said that she  
2235 missed it so much. And she said, "I love the way we talk with one another". When I  
2236 have people around on me I don't dwell on my problem. I was badly injured before  
2237 my diagnosis with breast cancer. I was in a wheel chair and I would get out of bed  
2238 and sit in this chair, watch television and that's all I used to do. One day my son  
2239 came home before he got married. That day I had thought seriously about committing  
2240 suicide, but didn't go through with it. When my son came home I told him about it.  
2241 And he said, "Mum every time I come through that front door I wonder if you're still  
2242 with us. When I leave for work your sitting there watching television and when I come  
2243 home from work your sitting there watching television. I am sick of it and if you don't  
2244 get off your fat backside you will be six feet under. What you need to do is you need  
2245 to get to some rehab". I was crying and he was saying, "There is no use crying to  
2246 me". Anyway he found out who to see and I met this guy and I fell in love with him.  
2247 So I was in rehab for a month and I improved dramatically. I had a psychologist,  
2248 physiotherapy, occupational therapy, hydrotherapy and I loved being there. I have  
2249 been going there for eight years and I really feel that if I don't go there I will really  
2250 drop dead.  
2251

2252 I think that the self-help groups are good because we are able to talk about stuff. We  
2253 have guest speakers and lecturers. One lady was from the anti-cancer council and  
2254 she came to talk about sexuality and she was wonderful. She was lovely and she  
2255 was saying was that what you have to do is say three things you like about yourself  
2256 when you get out of bed in the morning. And I was thinking, "three things, God I can't  
2257 even think of one thing". Then she looked at me and she said, "Kay I have seen how  
2258 old you are and you know what you can say, I haven't got a wrinkle on my face". I  
2259 thought about this and thought how nice.

2260

2261 **Tracey**

2262 *M: Please tell me about how you came to find out about your breast cancer.*

2263

2264 T: I remember finding out and feeling that the way they had told me was very raw,  
2265 very brutal. I was called in. I had the recall and it didn't dawn on me that I had cancer.  
2266 I was quite sure that they were just looking at nothing in particular. I suppose I was in  
2267 denial. There was a social worker who took notes for me when they called me back.  
2268 In a stressful situation it is reported that you don't remember what has been said. The  
2269 idea is to have someone with you who is separate from the situation who will  
2270 remember. The social worker was really nice. She sat me down afterwards, took me  
2271 to a room and made me a cuppa. At that stage I was in shock. And from that day  
2272 onwards I wandered around in a trance not knowing or believing or wondering. And I  
2273 didn't have the presence to go back to her, or talk to her, nor did she ever contact me  
2274 again. I went into depression for a year. It was all too much for me to look at cope  
2275 with.

2276

2277 *M: How did you cope with that?*

2278

2279 T: Oh time I suppose. I went along doing different things. I went to a foundation  
2280 residential breast cancer school. That helped me immensely.

2281

2282 *M: In what way?*

2283

2284 T: First of all it helped me realise I wasn't the only person who ever had breast  
2285 cancer. There were twenty-four women in the group. We all had had breast cancer at  
2286 some stage. Some were still dealing with it, experiencing, and working through breast  
2287 cancer in a natural way, in a non-surgical way. But we would sit in a circle everyday  
2288 and talk about issues. You had a chance to tell your story.

2289

2290 *M: How did you feel when you told your story?*

2291

2292 T: It was wonderful. I don't think anyone had ever asked me to tell my story before,  
2293 there was never the opportunity. Seldom do people come up to you and ask how it  
2294 has been. People might ask you how you are, but when you start telling them they  
2295 really don't want to know. And I remember I was in the middle of the group from  
2296 where Gen started and I thought there has been a lot of horror in my life and I can't  
2297 remember much joy, even now. That's the way it is. And getting the gist of what other  
2298 women were talking about I was thinking well I can say this and that, I won't bother  
2299 telling them about that... I was compiling a story. I was making my story up for the  
2300 audience, not for me.

2301

2302 When it got to my turn I sort of went somewhere else. And I started off when I was a  
2303 wee child probably three years old in my first memories and it just came out and it  
2304 didn't matter. You know when they talk about being detached you know sort of  
2305 looking at your life from another angle, another place, I was in that mode. In that

2306 stage I was able to talk about all those things that had upset me and how it was. And  
2307 it was just so matter of fact. It had a powerful impact on the group. Everyone went  
2308 into silence. Gen called a recession because my story was pretty awful. We stood up  
2309 and there is a practice in spirituality for when you have been opened up. There is a  
2310 lot of energy you know, changes that move about and it sits in your aurora. When this  
2311 happens you need to smooth back and calm and settle your aurora. They call this  
2312 combing the aurora. You know it is just a gentle moment with your hands, you don't  
2313 touch the person, just around them. So Gen got us to do this to get our emotions  
2314 back to where they belonged and to each other and we turned sideways so that the  
2315 girl behind you worked on you and you worked on the girl in front of you. When that  
2316 was happening I got this violent tremor like feeling, sensation. It was a sensation not  
2317 a feeling and I started to shake and tremble. It was all this emotion that had been  
2318 stuffed down and was coming out. They lay me on the floor in the centre of the circle  
2319 and I physically vibrated on the ground for ages.

2320

2321 *M: Was it a horrible feeling?*

2322

2323 T: Yeah it was terrible, frightening. And yet Gen knelt in front of me and Tilly behind  
2324 me and there was a calmness that came over me and they were talking me through  
2325 it. They were aware of what was happening as they had seen it before. But it doesn't  
2326 happen very often. And then I was tired and exhausted. I just wanted to go to bed  
2327 and cool off. We had a break for a cuppa then I calmed down and they told me to lie  
2328 on the floor where all the cushions were. I felt comfy in the circle, I felt supported.

2329

2330 *M: Was that a feeling you hadn't had for a long time?*

2331

2332 T: No I never had support. That was early afternoon and the next day I felt so light  
2333 and I had this feeling of lightness in my chest, like a big rock had gone away. It was  
2334 emotional, but I felt it physically. I was aware of the top of my chest and it just felt  
2335 light. It is hard to explain. You feel light and I was floating around and I have been  
2336 floating ever since. It was also suggested that we practice meditation to help facilitate  
2337 our stress.

2338

2339 *M: Did you meditate before?*

2340

2341 T: No, but I brought the book and taught myself to meditate in that time and from day  
2342 one I felt and found benefit. Again like it was supposed to be.

2343

2344 *M: Can you please talk about your feelings when you meditate. Why is it so good?*

2345

2346 T: I started meditating when I was diagnosed in 1984. Meditation led me to a lot of  
2347 self-realisations and I came to see that I did not hold a lot of negative attitudes. I also  
2348 started suffering from panic attacks shortly after my diagnosis and found that  
2349 meditation helped me to manage my panic attacks better....When I meditate I find  
2350 that place of peace of calm, of quiet. That sticker on my door 'I'm Shanti' means I  
2351 am soul as well as a body. I was told that shanti means peaceful, calm, happy and  
2352 there is a theory that our soul is peaceful, it is the peaceful part of us. We become  
2353 distressed and scattered and fragmented, but our inner essence is calm. And when  
2354 you meditate you can go to whatever part of your body or inside you that you feel is  
2355 the core of you. And you know when you have found it because you smile for no  
2356 apparent reason you know it is from within you. It not reliant on looking at a pretty  
2357 flower or smelling a nice smell or having eaten something nice, or somebody done  
2358 something nice for you. It is in you. It is inside you and you get to that spot and it is  
2359 lovely. So you want more of it and you practice every day.

2360

2361 Meditation makes you feel calm. It also allows the rest of the rubbish that you have  
2362 accumulated to come up and only then can you deal with it. It is only when you come  
2363 face to face with such raw emotions to do with breast cancer that you can let them  
2364 go, throw them in the wind so they can settle elsewhere. There is still anger that  
2365 comes up or sadness. A lot of sadness has come up for me. This sadness goes back  
2366 a while. And it comes up and I just feel so sad that I have to cry. And half the time I  
2367 don't know what I am crying for but I feel sad so I cry and it goes. Sometimes I do  
2368 know. I will have a memory of an incident and I will think heavens above that  
2369 happened forty years ago. This doesn't matter because these feelings are still in my  
2370 psyche. Once example was my nana, my mother's mother. We were very close. I  
2371 was only sixteen when she died. I would visit her every day because she was getting  
2372 forgetful. She only lived down the road so it was good to see her. Then nana got  
2373 more wandering, she had dementia and she went into a nursing home sixty miles  
2374 away. To cut a long story short I never saw her again and she died. She died the  
2375 night before I was meant to see her. I had booked the bus and all. So I am sixty soon  
2376 and I was sixteen when she died. It took me all those years to come to terms with the  
2377 fact that I missed my nana very much and what was it? Why didn't I grieve properly? I  
2378 mean I did grieve. I had this awful feeling for years and years that I would never see  
2379 her again and that was hard and possibly the basis of my breast cancer. It is amazing  
2380 that we can stuff things down so long. They say that breast cancer is unexpressed or  
2381 unfelt nurture

2382

2383 *M: What were you saying about the significance of the breast I didn't quite catch it*  
2384 *and grieving the loss of others...is that the nurturing side of a woman?*

2385

2386 T: Yes the feminine, the emotional. Yes grieving can be the foundation of your breast  
2387 cancer.

2388

2389 *M: So you attribute the reason you got breast cancer to a particular grievance you*  
2390 *hadn't dealt with. Are you saying that your breast cancer occurred because of not*  
2391 *coming to terms with your nana's death?*

2392

2393 T: Yes and also of not feeling love. There is another aspect of my life where I never  
2394 ever felt loved or wanted by my mother, like a rejection. Because of this I did find it  
2395 difficult to experience love because I didn't know how it felt or what it was like to be  
2396 loved, held or cuddled. I had some counselling that enabled me to come to terms  
2397 with these issues. I remember that during my depression I couldn't get out of bed. I  
2398 would get out of bed to have something to eat, go to the toilet and I would run back to  
2399 bed and pull the covers over me. I knew I shouldn't be doing it but I was doing it. I  
2400 would get dressed and I would make myself go out for walk. Then I would come  
2401 home and do the same thing again. I just couldn't function in the way I knew I could,  
2402 or should be. And I had a friend I used to work with who took a guardian angel type  
2403 role for me. She was a lot younger than me, but she always used to look out for me  
2404 and she used to ring me after I had surgery. It was through her that I got onto a  
2405 counsellor.

2406

2407 *M: What do you do during times when you feel threatened or are in pain?*

2408

2409 T: I often had panic attacks. And now I breathe consciously and go to that quiet calm  
2410 place inside and trust that this pain will pass. The panic attacks started somewhere  
2411 between surgery and my counselling. I didn't experience them before I did the breast  
2412 cancer workshop either. I had done that initial breaking of the encasement that was  
2413 around me that I held. It had broken so then the rest came up. And panic attacks I

2414 see as fear, fear that you're not in control. And again you don't know what it is from. It  
2415 will stop you in your tracks and is really severe. I remember the first really strong one.  
2416 I was in my bedroom and I walked around and I thought I was going to die and I  
2417 thought well I will be dying sitting down. And I just sort of sat and let it go and  
2418 experienced it and I thought wow what was that? And that was a good lesson  
2419 because subsequent ones have never been as strong. I have little mini ones now. I  
2420 know myself now and that goes back to our mutual terror and fear of my cancer  
2421 diagnosis of not knowing. And you associate, I associated cancer with dying, a lot of  
2422 people do. I was at a meeting once and someone asked me whether I was ok. I  
2423 replied by saying, "I am living not dying". I thought to myself, yes I am well, yes I can  
2424 do what I want to do and no I don't have to be frightened.

2425  
2426 *M: Are there any other things apart from meditation that you do when you feel*  
2427 *threatened or are in pain?*

2428  
2429 T: I am with district nursing at the moment and I love it. It has helped me with cancer.  
2430 It satisfies my need for not caring for my grandmother, not having my children around  
2431 me to care for, that nurturing side. This work is purely selfish. I do day shift and  
2432 rounds. We shower people in their homes. Before I was diagnosed with cancer I  
2433 worked with the local council for sixteen years. Prior to my diagnosis I had been tired  
2434 for six months and I was tired of being tired. I decided to take some long service  
2435 leave and then I set about having medical checkups and looking after myself better.  
2436 That was when I found out I had cancer. So I was starting to heal, or get back into  
2437 the mode to improve to get better. But, when I went back to my original job for a  
2438 week I knew that I didn't want to be there any more so I resigned, I retired in the  
2439 June. I then decided that I wanted a job that would be more rewarding which led me  
2440 to nursing.

2441  
2442 *M: Have there been any other major changes in you life that has taken place since*  
2443 *being diagnosed with cancer?*

2444  
2445 T: Sometimes I feel anxious about family gatherings because I like things to be nice  
2446 and right and I don't have any control over that. This causes me to be anxious when  
2447 things are out of my control. And I accept it more readily than I used to. I wanted to  
2448 control everybody and everything. Where as now I have just let things go. Before I  
2449 had breast cancer I was fanatical about how square everything was in the house. I  
2450 was also very critical of how things were and the way people behaved. Now I am  
2451 much more accepting of the way things are. It makes me feel a whole lot better. I feel  
2452 freer. I try to live for the moment, not even the hour, but the moment and that is  
2453 meditation. If you can concentrate on just now, you're free and don't have any  
2454 constrictions. So my meditation has helped me in that area too, to be accepting.  
2455 Another thing is that I had a Tarot card reading. The cards said that I needed to get in  
2456 touch with a religion or a God. I felt indignant when she told me this and thought I  
2457 know about God, I don't need you to tell me I need to do more. But then I found  
2458 myself doing more and thinking about God more and I started going to a spiritual  
2459 church.

2460  
2461 *M: Is this after or before your diagnosis with cancer?*

2462  
2463 T: After, just after. I would visit this church whenever I felt a need. This taught me  
2464 about spirituality. I have come now to believe that God is the father, the supreme  
2465 God and all these other religious leaders and founders all have their place, but the  
2466 supreme is God. This belief makes me feel connected, secure. I like the feeling of  
2467 belonging to someone.

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*M: When you wake up in the morning are there things that enable you to attain a sense of peacefulness?*

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**Lisa**

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*M: Please tell me about how you came to find out about your illness.*

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L: I found a lump in my breast. I had a needle aspiration and the results indicated that I had cancer. My sixteen-year-old son was being difficult and not helping me after surgery. He even said to me once, "Oh you're not dying". My daughter dealt with all of the problems by confronting them. She would read books about cancer and ask difficult questions. Looking back I can now see that my son did the reverse and ran away from it. He didn't want to know that I was sick and he was so distressed that he actually went the other way and pretended that everything was fine. He believed that I was just malingering and being a big nuisance. This made it really hard because he has been diabetic since he was seven and that has involved a lot of caring. I thought at the time that of all people you know how it feels when you are sick and vulnerable. He was not giving me any support and I felt really let down. I felt as though he didn't love me. I really felt absolutely rejected by the one person that I really thought would help a lot. Then he also told teachers at school that he was my full time carer and that's why he couldn't get his work done. And I just thought I can't cope with all of this when he is not lifting a finger to help me out. My daughter was living with her father and she would come around all the time and still try to do things. She stripped the walls and painted the kitchens for me so um I mean that's a lot for a sixteen-year old. I suppose I wanted my son to also help out and do little things, but he didn't.

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*M: What about when you were told about cancer, what was your reaction?*

L: The funny thing was that I felt the lump and I knew it was cancer. I supposed I just recognised it was quite different to anything I had before. So I went to my doctor and she felt it and she rang up immediately and made the appointment for the next day. So I really knew without having the needle aspiration. When I found out I was laughing and joking about it. Now the way I deal with things is that I go into a coping mode. If there is a problem I get on and solve it, I don't worry about it. My difficult stage comes after everything is over, even when there is no problem left. It is during this time that I start to worry and get upset. It's not denial. I don't dwell on problems, I deal with them and I guess I was laughing and joking. It sounds silly. And then I went home and the surgeon rang me over the weekend and broke the news over the phone. He handled it well and asked me if I wanted to bring a relative with me. The surgeon made it quite clear that the pathology results were not good. Eventually I saw him and following our meeting I decided to have a partial mastectomy. I also decided to have radiotherapy and then chemo.

*M: How did you feel once you had the partial mastectomy?*

L: Well it's interesting because just before all of that and reading the books I didn't realise how strong vanity comes into it. I really thought I don't want to lose my breasts and yet I've never really had strong sexual relationships. I have been divorced for some time and I don't have a lover at the moment, but it still was really important not to lose my breasts. The surgery was really good, probably because I am big and you don't really notice things too much, so I guess I am lucky.

*M: And when you were on the chemo were you very ill?*

L: I was very ill with chemo. After the chemo and the radiotherapy had finished I started to go down hill. I can remember being fairly stressed at that stage and I recognised in myself that I wasn't coping, I wasn't concentrating, I wasn't getting things done. I just thought what's the point of living? There is nothing I enjoy, there is nothing I want to do and none of my family loved me. I think one of the things that triggered it was I'd always felt my kids really needed me. All of a sudden I felt that I wasn't needed. At the time I had cancer my son went to live with my ex-husband. That was horrendous and it felt as if my whole world was collapsing. I really felt deserted.

*M: How did you cope with that?*

L: I slept a lot, listened to the radio, but I really wanted to make myself better. Actually I think I started swimming and I found it really relaxing, just lovely. Even though I didn't have pain with breast cancer, it was really quite frightening discovering how dependant I was on other people. It was also hard discovering that there wasn't anyone to do everything for you, rather you had to do it yourself. I had to get myself better. I wanted work and I couldn't get any work, but at the same time I felt I couldn't cope with much work because I felt so sick. And at that stage I think I was really thinking if I am going to die in a year or two then maybe um I've got to be around for the kids so I shouldn't work. So you have all these mixed up feelings because I didn't believe I was going to die. Yet, at the same time I was thinking there is a possibility. Then I started applying for jobs and I couldn't get work. I decided to go back to uni and do something I enjoyed. So I went back to study and I am sure the study did help me to get better.

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*M: Were there any other major events that took place after having breast cancer? You mentioned that your studies helped you to get through your depression.*

*L: I am a person that really likes to plan everything. I can also change my plans so if I have my life mapped out and something changes I'll change direction. But, I think associated with that there was a lot of worry, always has been about how I am going to survive financially. I think I started looking at this business with you know get on with life and stop worrying about the future. I am really putting that into practice. I believe my cancer's gone, hopefully it will never come back. I will have my checkups and make sure, but if it did come back next year or in five years, I don't want to have wasted this time so I really want to get on and do what I can and money really isn't important to me.*

*M: Were there any sources that helped you to feel better about yourself?*

*L: I got a puppy. My dog was something positive and really good for all of us. I take him to the beach most days for exercise. What one should do is get out and exercise. Having a dog forces you to exercise. I take my dog for walks down to the beach and I do so enjoy the beach. It is almost like meditation. I mean I went to meditation classes and stuff like that, but just walking on the beach is lovely and so relaxing. Another thing was that I started to go to support groups. But this soon began to effect me because I was worrying too much about the people there. With the cancer support group I felt like I needed to be able to talk and find out more about the cancer. Initially I went for me and it was really good just hearing how other people were dealing with things. It was also good hearing that they had problems too because I kept thinking the way I was feeling was my entire fault. So I think that understanding that I wasn't the only one going through it really made that difference. And then after a while I didn't need it so much. I went through the stage of having enough and feeling that there was more to life than cancer. I then decided I had to get away and start thinking of other things. It was a gradual thing.*

*M: When you were at the support group and you told your story how did that make you feel?*

*L: It was great to get everything out and to share my thoughts with others. I realise that I really need to have relationships with people and I need to feel needed. I have to feel I am making some sort of contribution and so just going through the rigmarole of everyday living you know you have to have purpose. And one of the things that I'd thought a lot about when I was going through this down period was that I felt I could identify with these very young people. You know when they leave school and they haven't got jobs and they feel what's the point? I was really thinking like that. Everything was wrong. Now things are better. I am now the treasurer for the local yacht club because me father asked me to do that. I think we need a quest in life, something that will make you feel that you have achieved certain goals.*

*M: And what about your father, your relationship with your father. How has that been effected by your illness?*

*L: My father is seventy-nine years old and he is very fit. There is a complete breakdown in the relationship between him and my sister. He comes round, walks the dogs with me, he got me walking on the beach. He was the motivating factor of actually getting me out and doing something.*

2630 *M: Were you always close with your dad?*

2631

2632 L: Yes and no. He is a funny man. He is very quiet and he always thinks he knows  
2633 best. I suppose that is a family tendency. But I think he has mellowed a lot. And um  
2634 even being a treasurer that is something worthwhile.

2635

2636 *M: So your relationship with your father has improved?*

2637

2638 L: Yes and in fact we don't discuss my illness. He has always had the belief that  
2639 exercise will make you better. He wants to live longer by exercising and keeping  
2640 mentally fit. He talks about the brain a lot. He says that if you exercise the brain a lot  
2641 you will keep healthy. But if you just sit around and do nothing that's no good. This  
2642 outlook has been very positive. And our relationship has improved a lot and I have  
2643 found that I have been able to talk to him about things not related to me that have  
2644 been of support to him.

2645

2646 *M: And what of your friends, have they been supportive?*

2647

2648 L: I don't have a lot of friends. Jill is a close friend and that's good. We talk about  
2649 anything and she has been there for me. We don't live in each other's pockets, but  
2650 we can depend on each other.

2651

2652 *M: What about religion or faith? Did that come into your life since breast cancer?*

2653

2654 L: I used to think I was religious in the sense that I have a spiritual belief. Whilst I  
2655 don't have a church going belief or a belief in God as such, I do believe that we are  
2656 here to benefit each other. I think I had a loss of faith after breast cancer. The reason  
2657 being people I came across didn't really care what was happening to me, or other  
2658 people. I just think we need to encourage people to do things for each other, look  
2659 after the environment that sort of stuff. I don't have belief in a higher being. I believe if  
2660 I died tomorrow my reincarnation to me means what the people I leave behind  
2661 remember about me. So I have to make sure that what I do is worthwhile. I don't  
2662 want them to have negative memories of me. As a mathematician I know that we live  
2663 in a world that we don't understand and I have no idea what is beyond us. We can  
2664 only understand what we experience so all our experiences should be worthwhile  
2665 and treasured.

2666

2667 **Carol**

2668 *M: Please tell me how you came to find out about your breast cancer and how you*  
2669 *felt at the time.*

2670

2671 C: I had a small lump on my left breast and I went and harassed the G.P and told her  
2672 I want a mammogram because of my history. She said that she thought I was too  
2673 young to have breast cancer. My G.P said it is just a hormonal lump, it will be fine  
2674 don't worry about it. She told me to take vitamin B6 for six weeks and see how the  
2675 lump goes. I did it for two weeks and thought blow this I don't want to muck around  
2676 with this lump. So I went and had a mammogram on the outer side. In my armpit  
2677 there were a cluster of cells that weren't normal. I decided to see a breast surgeon. I  
2678 got it biopsied. It turned out that it was indeed cancer. By about August I had surgery  
2679 and I had a lumpectomy. By November I had five weeks of radiotherapy. It took most  
2680 of the year to get through what I thought should have happened very quickly. I was  
2681 lucky as we got the breast cancer quite early. I only found it because of the other  
2682 lump that had presented so it was pure luck that I found it. I reckon if I had gone  
2683 ahead and got pregnant it could have sped it up because it was highly positive

estrogen. By the end of November I had finished the treatment. This year I got a lump on my thyroid which wasn't much fun because of the panic I got from my first doctor who said it is a ninety per cent chance that it is cancer. I got a second opinion from another doctor who said that it was more like twenty per cent. So I have had a rather stressful couple of years.

*M: When you first found out how did you feel?*

C: It was a sense of relief. I know it sounds funny but I had kind of been waiting for it all my life and I think that is a bad way to be, but deep down that is what I had been anticipating. My mum and grandmother both died of breast cancer so I had a feeling that I would get it some day. Whilst it was an incredible relief there was also this fear and dread of me dying. There was an overwhelming fear as well. All I could think about was Damien, my son, at two motherless, him not having a mother. I was sixteen when my mother died of breast cancer. At least I had had some time to get to know my mother. But I thought there wouldn't even be a memory of me if I died and my son was two. That was less of a problem than who would look after him. I know my husband would be an excellent parent, but he had to earn the money and he would have to change his whole lifestyle to fit in with Damien. Damien being looked after by a stepmother was also a big fear. I would be really scared if that person was not treating Damien with respect. So it was very important for me to outline to my husband how I felt about dying and who would raise our child. If I didn't have a child, I think it would be completely different. I would be very sad to think I might die early, but I know that my husband would cope, but to think of a little child.

I have seen mothers sitting on beaches with their children and I am so jealous, I know that it is terrible to feel that way because it is not fair. I get so envious. I just love my mum. I have had lots of help to work out this stuff but you never ever get over it. You get on with life but when you are asked confronting questions, this is when you let down the guard and open up. It is great when friends ask me because hardly any people ever ask you about your past history. I have lost six members of my family in three years and I became really blasé towards death.

When I went to nursing school and confronted death and dying I completely cracked it and had to get help and that was the best thing ever because someone confronted me with it. And I have learnt ever since then to get help, open up, get professional help, don't get crappy help. I watched my husband go through his father's illness and it was incredible. When my father in law was dying his family depended on me for support because of my nursing experience and I found that stressful. My son wasn't sleeping and I feel that was the start of my breast cancer development because they say stress contributes. The birth was traumatic and the first year of being a mother I found horrendously traumatic. I found there was all this stuff going on and I couldn't cope and I got some help. I was suffering from postnatal depression. I have always sort of done self-help stuff and it is a slow journey, but I am getting there and I am happy with my life. I am doing really well and I love my son and I am not going to let it go. I think that is one of my biggest drives.

Generally I think I have learnt so much from talking to people and listening to people. I was going to a support group and I had to drop out of that because I started to feel like I was moving on and getting back to normal life so I felt I wanted a break. I feel like dropping out of the support group I go to now. I am much healthier than a lot of women there. There are some women who are seriously ill. I get quite depressed when I go there. And I like the group but my worries now are more trivial compared to them. So when I pipe up and say I don't know whether to have another baby, well

2738 most of them can't have another baby. It might be bad for them to see me. There is  
2739 one woman there who has been only once. Yet, she feels very intimidated by the  
2740 meetings. It is about power. They get straight into the guts like we are talking about  
2741 death, but I think it is a bit too powerful and confronting sometimes for some of the  
2742 girls because they crack up. It is good to crack up, but sometimes it is not that  
2743 positive. You go away with heavy shoulders and exhausted and it is Friday night and  
2744 I wish it could be on another night.

2745

2746 *M: So initially when you attended the support group did you have different feelings?*

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2748 C: I have only been to three meetings. I let go and tell my story, but sometimes I feel  
2749 that everyone has their own agenda and they are a bit introverted. They are into it for  
2750 themselves. There is one girl who brings up the same thing every time we meet and  
2751 we tell her please go and get a second opinion. But the same things keep on coming  
2752 up in meetings and I am worried that we open up cans of worms but we don't clean  
2753 them up. She is repetitive. There is a frustration building up about why she won't do  
2754 something. I think some people have been pushed away because they are scared of  
2755 opening up to people. So whilst there are good things that can come of a group there  
2756 are also negative things. So depending upon the nature of the person who goes into  
2757 this group this will determine how they react and what they get out of it. And that  
2758 worries me a bit. I am a nurturer. It is nice but it can get you into hot water.

2759

2760 *M: Have you resolved certain aspects in your life that up until now have never been*  
2761 *resolved?*

2762

2763 C: Breast cancer is tricky because you never know when it is going to happen again.  
2764 That is the scariest thing about breast cancer, not knowing. The issue about my son,  
2765 I am going to be perpetually anxious about him not having a mother, but I am trying  
2766 to come to grips with that. I think some days are really good where I think I am going  
2767 to live for ever and then other days I don't cope that well. A million emotions can  
2768 happen in a day. I have a great fear of anxiety. One co-coordinator spoke about  
2769 people doing much better if they had a religious faith and that annoyed me a bit. I  
2770 don't know what I have in terms of my religious faith but I know I am a spiritual  
2771 person. I often don't have enough time to contemplate it. I did try meditation but  
2772 found the time to do it was difficult. I find it takes a lot of energy to think about these  
2773 things. I found meditation really good. It was fantastic and I was doing it quite  
2774 regularly for a while and then I got out of the habit and it was noticeable. I think I was  
2775 becoming a lot calmer and now I have reverted up again. I am a lot calmer now and I  
2776 am managing my life a lot better.

2777

2778 Getting breast cancer made me reassess everything. I decided there were friends I  
2779 can't be bothered with any more. I am stronger at making decisions about difficult  
2780 things. My family has become really important. And my sisters have become really  
2781 important. Also I think I never had the roots of a home basis to go to. I had this  
2782 incredible habit of picking up friends and using that as a parent like environment but  
2783 drifting, going from group to group and now I realise that my husband has a  
2784 wonderful strong family and I like being with them. I also feel that you can go over the  
2785 top with family. I now know that I have a support network with people in the street. I  
2786 would ask for help now if I needed whereas before I wouldn't. I was so depressed  
2787 before and I would sit at the phone sobbing and I couldn't cope. It was self-  
2788 destructive.

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2790 *M: Now you said something interesting before about your friends. Why is it that you*  
2791 *accepted them before and with cancer you chose to cut them off?*

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C: You have been friends because you obviously get things from them, but you realise that that is all trivial and just crap and so you think what is the point. Or you realise you have tolerated their materialism, but now what is the point of tolerating that? Now I need to rationalise my expenditure of energy. You are often very tired after radiotherapy and it is more important to look after yourself and those closest to you. Cancer has been a very powerful thing. And the other thing is I have this friend who I hardly ever see because my husband thinks they are painful. I think they are very nice people. I have a broad range of friends of different types of people. Anyway we hardly ever speak and when we do we get straight to the point, straight to the nuts and bolts and talk about the most deep and meaningful things. This friend is very religious and I am not. She is always making me think about things. When I come away from her I start confronting deep questions for myself. If she has the same problem she will definitely call on her religion to help her get through it. I haven't done that. I think I get through by I have a certain spirituality. I am very big on nature and I am a bit more of a Buddhist if I am going to any religion. I have done some reading and I like what they offer and it makes more sense to me than my Christian background. So nature for me is healing. I feel claustrophobic at times and I need to get out in the open air. I am a country girl I was brought up on a farm, I love open spaces and I think that is my spirituality. I have a great interest in American Indians and read a lot about their life and how they relate to the earth and their spirituality.

*M: When you feel threatened and in pain what do you do?*

C: I confront it and find out as much as I can about it. If it is not fixable I want to know as much as I can to work out a way for me to cope with it. I am a very big information gatherer. I am not a person who puts my head in the sand.

*M: Please tell me about your husband and how he has coped with your breast cancer.*

C: My husband has been wonderful but I think he is a typical man. His reaction is it will be o.k., we will move on. And yet I have explained to him over and over again that the fear doesn't go away. While I am alive I can get it again. So how can you just move on? He knows he shouldn't think like that but he does. If I am feeling grumpy I will tell him why and keep him informed he understands.

*M: Are there any issues to do with sexuality?*

C: Not much I have had a lot of problems with sexuality and this is confidential. We have had sex about three times in two years. It hasn't been great but my husband is wonderful and totally understanding. When I was seventeen my guardian was my sister's husband and he sexually abused me after I had lost all my family. So at seventeen I was a big girl, but a baby. So that has probably been my biggest struggle. I have made that sexual abuse period, which was only one week when my sisters was in hospital, an excuse for other things to be bad. So I have had lots of help to work out. But it hasn't helped my sexual life. He says let's move on. Forget about your sister's husband. He can't see that after twenty-two years I still dwell on it. I never told my sister and I feel guilty about that. I didn't tell anyone for years.

*M: Please tell me about a time you felt good about yourself.*

2845 C: The last three weeks I have been well. I went for a run with Damien and his bike  
2846 down the beach. I am getting exercise. It was a beautiful day and I felt great. Feeling  
2847 really energetic.

2848  
2849 *M: When you are feeling bad what helps you?*

2850  
2851 C: I think I am not going to let it beat me. The reality of running a house can be so  
2852 overwhelming at times. If I am feeling really bad, getting outside helps. If I am too  
2853 miserable I don't even get outside. I love swimming. I feel swimming meditational. I  
2854 like to train. I love going to coffee shops by myself. That is a big outlet for me. When  
2855 my son was little I was able to do that. I cherish my private space and when I don't  
2856 get it I cave in and I get desperate to get some space. I need my independence.  
2857 Breast cancer has made me more tolerant. It teaches you to not push yourself so  
2858 hard.

2859  
2860 *M: I have heard that when you get a diagnosis with cancer you become selfish? Has*  
2861 *this occurred with you?*

2862  
2863 C: Yeah I think I recognise I need to say no a whole lot more. My biggest problem is  
2864 that I have said yes to everyone. Having a baby started to confuse me and I lost sight  
2865 of who I was. But the breast cancer thing put the boot in and told me I have to make  
2866 some changes. I got out of my work. I am much happier. I think it has been a really  
2867 positive thing. I reckon if I don't get it again it has been a positive thing. Valuing what  
2868 you are is really positive. I like myself more now. I have had a bad time with self-  
2869 esteem but I am working to improve this.

2870  
2871 **Belinda**

2872 *M: Please tell me how you were firstly diagnosed? How did you feel?*

2873  
2874 B: Originally I found my own lump in my breast whilst in the shower. I spoke to my  
2875 husband about it. We were in Adelaide at the time with our work and we had already  
2876 been told that we were moving back to Melbourne by that stage. So we moved to  
2877 Melbourne and in the first week of February in 1997 I went to see a doctor. He  
2878 checked it out and wasn't happy with it. He said that I should go straight away to get  
2879 a mammogram and ultra sound on that day and bring the results back straight away  
2880 so I was really pleased about. The tests were inconclusive. They couldn't tell whether  
2881 it was a benign or a malignant lump from the test. I got booked into seeing a surgeon  
2882 the next day and I had a needle aspiration. The surgeon said, "Whether the results  
2883 are positive or negative, I can tell you now you have breast cancer". She spoke to me  
2884 about my options and said come back on Monday and we will go through it again  
2885 with the results and see how we go. So on the Monday I went back. On the Thursday  
2886 I had a lumpectomy. When she actually opened me up the tumor had grown a bridge  
2887 and started again. The surgeon had to take a much larger section then she had  
2888 originally thought. I then went back a few days later and had a mastectomy so that is  
2889 how it started initially.

2890  
2891 As far as how I felt, I am a Christian and have very strong faith and it was really  
2892 interesting because when we got told we were leaving Adelaide before I even found  
2893 the lump in the November I was really shattered. We had only been in the job we  
2894 were in for one year. We work for the Salvation Army and we were looking after the  
2895 youth program for the whole of Adelaide. We were just finding our feet and we were  
2896 told we would have to move to Melbourne to then become the next layer up. Also my  
2897 mother was living in Adelaide. I had only spent the one-year with her and I was  
2898 enjoying the relationship that we had. We were settling into our church there and the

2899 kids had settled in at school so I was quite shattered in the beginning but I had an  
2900 experience at that time of absolute reassurance that God was going to look after me.  
2901 I was only in my job for one week when I found out I had breast cancer. Then I knew  
2902 why I was out here because there were doctors who knew me and I was with this  
2903 great surgeon and all that sort of jazz.

2904  
2905 So right from the word go when she told me, when she turned around after having  
2906 done the needle aspiration and looked at me in the eye and he said, "Belinda I am  
2907 ninety-nine point nine per cent sure you have breast cancer". I was just able to say,  
2908 "It's o.k, God's in control". That's just exactly how I felt. It was just amazing I mean  
2909 when I was a little girl, cancer was the big 'C' word and I thought how could anyone  
2910 cope with it, it would be just the most awful thing you could ever get. And it was just  
2911 amazing when the reality hit. I said to my husband, you would never actually wish  
2912 this upon your worst enemy; it's not something you ask for. But in it becoming part of  
2913 my life I felt it was an opportunity to put my faith in God. I had actually written in my  
2914 journal a couple of months before that I wanted God to teach me to trust him more so  
2915 I thought here is my opportunity so that's how it all started.

2916  
2917 I had my first mastectomy in February 1997. I had chemo and radiation for that  
2918 because it was fairly invasive. That finished in about September and then in the  
2919 November I felt other lump in the other arm. Although my left breast showed no sign  
2920 of tumor at all, most of the nodes in the left arm had cancer in them so we had to  
2921 remove them as well. I had a 'CAT' scan, bone scan, the chest x-ray and there was  
2922 no sign of tumors anywhere else in my body so we decided not to have any  
2923 chemotherapy during that time. In the April that year I was in Adelaide for a holiday  
2924 and when I drove home I had this really bad back and thought it was just because I  
2925 was sitting in the car. It just got worse and worse and worse and with investigation  
2926 we discovered the breast cancer had now spread to my bones. So I had it right down  
2927 through my spine and through my hips. So I had a second course of chemotherapy  
2928 and lost my hair for the second year in a row. That was a bit tragic. I was on 180mg  
2929 of Morphine at that time for over a year because of the pain from the bones. We  
2930 moved on in that second year. I never got a period during the time I was on taxotear,  
2931 but out of the blue on Christmas day I got a period. A month after that my left breast  
2932 just changed, whatever lumps were there before had turned cancerous.

2933  
2934 I had my second mastectomy exactly two years and one day from the first one. That  
2935 was February 1999. And there were still no signs of anything going on too much. But,  
2936 because of my history my surgeon suggested that I take a high dose of chemo. I did  
2937 that and I lost my hair again and that put me in total remission as they call it. I spent  
2938 from September last year to May 2000 recovering. It takes a long time but getting to  
2939 the stage where I was going to work a couple of days again and feeling really good.  
2940 And then I had a couple of funny feelings in my head and some funny situations and  
2941 then a headache like someone was squeezing my brain. I went and had that  
2942 investigated and was told that I had two brain tumors. The little one could be done  
2943 with radiation, but the big one they said was best to be operated on. I had a MRI and  
2944 the doctor found five little ones. And within the first week I had the brain tumor  
2945 removed, I have been really well since and lost my hair again for the forth year in a  
2946 row. I just finished radiation a week ago. The radiation builds up and builds up, then it  
2947 slows down so my skin is really itchy and dry. I have very dry eyes and a dry mouth  
2948 but on the whole I have coped really well. Tiredness is the big factor, but I am doing  
2949 really well and I can't believe how well I got over the operation. I had it on the  
2950 Monday and came home on the Saturday and have been terrific ever since.

2951

2952 It has been interesting in belonging to a group where everyone shares their stories. I  
2953 get several of the breast cancer action groups magazines and it is really encouraging  
2954 to read some of their stories and realise that people have been through similar things  
2955 and are doing really well. Sharing and getting a wider network of people whose  
2956 stories I am hearing is encouraging to me. And we have had to learn to love basically  
2957 a day at a time. We plan down the track, but I say to people always just understand  
2958 that I can't do things sometimes. I find I suppose going back to the faith issue that I  
2959 am learning to live the way we all should live anyway, realising that each day is a gift  
2960 and none of us knows how long we have and each of us should live to the full. And I  
2961 said to mum the other day and I know people don't believe it when I say it but I would  
2962 have to say that the last few weeks have probably been amongst the happiest of my  
2963 life. Just the way I have felt incredibly carried along. I have been blessed so much  
2964 and lovely little things have been done that reassures me that God is in control and I  
2965 guess being a Christian I feel very much that this is only one part of life and life will  
2966 not finish with the day I die. And because I sort of have really asked the Lord to have  
2967 an eternal perspective both to my life and really to the whole thing I don't fear the  
2968 potential of what could happen. He knows I have three boys who I would love to see  
2969 grow up, I would love to hold my grandchildren in my arms, but in a sense if it doesn't  
2970 happen it won't be the end of the world.

2971  
2972 At the end of the first year when I found out I had secondaries and didn't know much  
2973 about breast cancer at all, I thought I will be lucky to live to next Christmas, I just  
2974 thought that every one dies. I have been going three and a half years inspite of what  
2975 has happened to me and feel very well. My blood count is really good so and I am  
2976 fortunate that there are no signs of tumors in my lungs or liver and that's really  
2977 important because they are vital organs you cant live without. At my absolute worst if  
2978 the tumor has eaten away my hips and I would have to sit in a wheel chair well that  
2979 could be the worst, but you are still alive. So at the moment as long as the tumor  
2980 stays away from these two places I thank God and think I could live for years like this  
2981 and that's my plan to live one day at a time. I have read several books about people  
2982 and their fight with cancer. One being a very strong Christian man who got cancer  
2983 and had these real famous faith healers travel from America to England to pray over  
2984 him. He died anyway. People kept on saying to him why you? You are a great writer  
2985 and a great man of faith why you? And as he was going through the journey he  
2986 started to say I have discovered there are no questions to the why questions. My  
2987 philosophy is that I live in a world that has been broken down by sin and good people  
2988 and bad people get the rain and the sun so why not me any more than anyone else.  
2989 So I don't feel just because I am a Christian that I should be exempt or protected  
2990 than anyone else. If this was the case everyone would be a Christian so they would  
2991 be protected and they wouldn't be a Christian for the right reasons. So I tend to agree  
2992 with this writer. I have no problem with that sort of philosophy in fact I find it  
2993 distressing when people say to me, "But why you?" I don't choose to think like that, I  
2994 choose to believe.

2995  
2996 Underlying all my life over a period of time I have built up a philosophy of life that  
2997 God is interested, has my best interest at heart. God's has an eternal interest in me  
2998 and not just an earthly one. This interest is not going to stop once I die and it is not  
2999 just attached to my illness. The most important thing is my ability to trust God in all of  
3000 this that maybe when their problems arise I will be encouraged. So I suppose right  
3001 from the word go what I did say if I have to have this thing, please make this thing  
3002 mean something. I mean I couldn't stand the thought of having breast cancer and it  
3003 meant nothing. I mean the fact that I can accept all of this to me is an answer to  
3004 prayer. But, the doctors say that once you have secondary cancer there is no cure.  
3005 All we can do is keep it under control for as long as we can. For some people it is

3006 thirty years, for many it is less. The average is about two years. But, for some people  
3007 it is years and years. So I try to say to them well I am being healed in lots of ways.  
3008 And the fact that I can have such a positive attitude to all of this is part of that  
3009 healing. And I said to them we have to remember if I didn't have this is that going to  
3010 make my life any better? Just the absence of cancer I might become selfish. I think it  
3011 is interesting what sometimes we think would make our life better. Sometimes we  
3012 think it is the absence of anything that is painful, or anything that is distressing and I  
3013 don't agree with that. I think that it is in the tough times that that's when we grow as a  
3014 person and become a better person. So actually in a sense I would like to live a long  
3015 time, but I don't see that as the ultimate answer to prayer.

3016  
3017 I was forty when I got it. There have been different things that have happened to me  
3018 to prepare me for this. I have been a Salvation Army Officer, which is like a minister  
3019 of religion for nearly twenty years now, and all the things I learnt during that time, all  
3020 the times I preached, I mean I was preaching to myself too. In preaching I had this  
3021 incredibly strong foundation when cancer came. I think it has been like a gift to me  
3022 and what I say to other people is while things are good build on the foundation so  
3023 that when things get tough and they are bound to sometime you have something to  
3024 fall back on.

3025  
3026 *M: Have there been any major events that have taken place since firstly being*  
3027 *diagnosed?*  
3028

3029 B: Coping with each new reoccurrence is probably the main factor. On the whole it  
3030 has been a positive three and a half years. The one most significant thing that has  
3031 happened to me in the last few years is a study. I joined that one-year after I was  
3032 diagnosed. Because I had the secondaries, my surgeon was able to say you would  
3033 be able to join this group and I have been in it for over two years now. What  
3034 happened when I joined this group was that I walked in the door and met ladies who  
3035 lived with cancer and that was a really good thing because at the time I was thinking  
3036 how long do I have to live. I remember sitting here on Christmas day of that year after  
3037 I had that nodes removed. All my brothers and sisters were singing carols and  
3038 praying together and I just looked at them and I wanted to say hang on to this as this  
3039 might be the last year it will be like this. I had to go out and cry, but I didn't tell them. I  
3040 had no idea anyway and assumed that everyone who gets secondary breast cancer  
3041 dies. When I went to my first breast cancer meeting and found out all the ladies  
3042 stories I was blown away and realised that people live with this thing and move on.  
3043 And it has been a really really good thing for relationships and support. We have  
3044 lunch together and we spend quite a bit of time on the phone in between and there is  
3045 lots of encouragement in the hospital and they will visit and all that sort of stuff. But  
3046 the other thing it has done is it has given us quite a broad education about breast  
3047 cancer. We have all been able to share our bits and pieces and we are actually quite  
3048 well educated about the whole thing, about treatments and what cancer is and how  
3049 things work. So what it really freed me up to do is go to the doctor and ask questions  
3050 that in the past I would never have thought of asking. I probably wouldn't have had  
3051 the courage to and to also be quite assertive and say, "No I don't want that and yes I  
3052 want that and will you do this before that". I really found that to be freeing and it has  
3053 also given me courage. And the other reason is that sense of assertiveness.

3054  
3055 I have always been a peacemaker and I am by nature a peacemaker. I used to avoid  
3056 conflict, but now I am willing if I need to be up front. When you have an operation for  
3057 a brain tumor they sometimes cut your jaw and I had no idea till I woke up and  
3058 thought they had pulled out every tooth out of my right side. I couldn't eat for a couple  
3059 of days. And the next day they gave me this piece of paper all typed up to say that in

3060 the operation I had my jaw muscles cut and these are the exercises to do and I  
3061 thought why didn't they tell me. When the surgeon came to see I said to the doctor,  
3062 "Please don't take this as a criticism but I am the sort of person who rather know  
3063 everything that is going to happen beforehand so that I know what I am going to be  
3064 up for. I know that some people don't want to know anything and that makes it hard  
3065 for you, but if you supply me with a piece of paper regarding my jaw it must happen  
3066 more than once. It wasn't something you found you had to do to me. I am just  
3067 wondering if you could let people know that that might be the case. Then when you  
3068 come out of that awful operation you understand why you're feeling the way you  
3069 feel". And he said, "Yeah that's true I take your point we should tell people and it  
3070 would make it easier for them". Three years ago I would go to the doctors and say  
3071 yes sir, no sir, three bags full sir. Anything they told me to do I would do. I would  
3072 never challenge, never question because doctors are doctors they know everything  
3073 but now I don't agree with that.

3074  
3075 There are also some people who I avoid a bit because they are negative and tiring  
3076 and they are just so exhausting because of the way they talk. Sometimes I have  
3077 decided to distance myself from these kinds of people. One example is my in-laws.  
3078 They are beautiful people who over love me and my father in law gives me those  
3079 over extended hugs like it's the last hug he will have. I know he needs to do that, but  
3080 for me it gives me the feeling that I am not going to live long and I don't need that  
3081 negativity. They would ring up all the time and it was very draining and then they  
3082 would come and visit me and treat me like an invalid and they have to look after me.  
3083 I don't want to feel that I am a sick person when I am feeling well. Anyway I  
3084 discussed it one day with my husband and I said it is just wearing me out. I can't  
3085 meet their needs because I have needs of my own. I can't cope with their need to  
3086 feel needed as opposed to my need to feel normal and I just can't do it. He told them  
3087 and my in laws took it so personally and we didn't speak to them for the next six  
3088 weeks. Word got around that we didn't appreciate them and we had to deal with that.  
3089 We eventually got over it, but they are getting back to what they used to do. That has  
3090 been one of the hardest relationships I have had. Most of my friends have been great  
3091 and supportive. Immediately I had problems with cancer and they set up a roster at  
3092 my church to do my housework and that was great. So we have been incredibly well  
3093 supported. My neighbour has passed away since and we sort of journeyed together.  
3094 At Christmas time she got secondaries and died very quickly. I mean that is the one  
3095 problem depending on how it occurs, it can be so unpredictable.

3096  
3097 M: What do you do during times when you feel threatened or are in pain?  
3098

3099 B: A few times at the beginning, when I was just trying to come to terms with  
3100 everything, I found my self-lying on my bed holding my bible. One of the things that  
3101 has been really special to me has been the twenty-third psalm at it says 'The lord is  
3102 my shepherd and I have everything I need'. I would lie on my bed and cry and hold  
3103 my lamb and say it over and over and remind myself that God was in control. Then I  
3104 felt I could move on. That is one thing that I do. I have lots of favourite passages of  
3105 Scripture that I will read to myself to remind myself to keep it all in perspective. I cry  
3106 when I need to, I let it all out when I need to. I cried when I shaved my head for the  
3107 fourth year in a row. I admit I said to the Lord, "I am sick of this, I have had enough". I  
3108 used to have long blonde hair and I used to perm it. For four years now I have had  
3109 three haircuts, but twice. I didn't even get to the point of having a hair cut. I wouldn't  
3110 say I prided myself in my hair in the sense, but I had lovely hair that I used to do up.

3111  
3112 Even with other people I have talked to, they have said that they could cope with the  
3113 loss of a boob, but losing the hair was the worst part. I guess because you can hide

3114 the fact of what's underneath clothes. But, having no hair is so in your face in that it is  
3115 a constant reminder of what you are going through. I guess in some way it dints your  
3116 womanhood. I walk around the house now in my pyjamas and never wear my boobs  
3117 or anything. I am just flat and I sometimes laugh and say to my husband, "It must be  
3118 like sleeping with your son". But, that I can handle because I can deal with it. I can  
3119 put boobs on and look like a woman, but the fact that you just have no hair. It doesn't  
3120 matter how many people tell you that your head is a good shape for it, it is just not  
3121 me. It is just not what I imagined for myself. But, I have handled it over the years. I  
3122 have a nice wig I've got great hats. I have a real nice hat that I wear. It is really  
3123 dressy. This hat is gorgeous and glamorous and I feel really good in it so I get away  
3124 with it. Yesterday it was the first time I wore it. I wear it to church all the time, and I  
3125 wore it down the street and I was surprised at the amount of people that looked at  
3126 me. It was an interesting reaction from people. On the whole I suppose it is truly my  
3127 faith and this underlying belief that God knows what he is doing and is in control. This  
3128 knowledge keeps me going.

3129

3130 *M: Do you meditate?*

3131

3132 B: Yes I often do. Generally relaxation type stuff and when they talk about seeing the  
3133 white light I sort of turn that into my Christian aspect so that I am sort of meditating  
3134 about God. I read a lot and I try to read books that will be of encouragement. People  
3135 have given me some good books. My husband has been magnificent. He really has  
3136 been an incredible support and has never given me one minute's feeling that I am  
3137 less than what I ever was to him. However, I do think he copes best when I am  
3138 coping and it will be interesting to see how things unravel. I am very aware that I  
3139 need to allow him to share his feelings. He doesn't share them with me. I know he  
3140 will often share his own sort of pain with his friends, but he doesn't like to tell me. I  
3141 think he doesn't want to burden me, but sometimes I would like to know how he is  
3142 feeling. We have talked to the boys about the possibility of dying they know that is  
3143 the case and I try and get them to talk to me about anything. Anytime they have any  
3144 issues I try and leave the communication open. I want them to be very open about it,  
3145 but I do recognize that there might come a time when we will have to sit down and  
3146 say this is the way it is. There may come a time when we don't know how long I have  
3147 to live, but this is the way it is so lets make sure that every moment we spend is as a  
3148 family.

3149

3150 My sons have been brilliant. They have helped out with physical things, but it is more  
3151 emotional. They will come and lie on the bed with me and they give me lots of hugs  
3152 and kisses. They have always been quite affectionate. I remember after my first  
3153 operation we were sitting in a church meeting and one of my sons had gone to the  
3154 toilet. He came back past and as he walked past me he rubbed my back. Just the  
3155 thought of that was really lovely. We have always been really affectionate, but it  
3156 wasn't specific in that sense and now they recognise mum has this need. And we  
3157 have had our jokes. When I first brought my first prosthesis home my sixteen year old  
3158 son said do you think I could take it to bed, I haven't had a girlfriend in a while. We  
3159 laugh a lot, and I have told them all sorts of funny jokes and I have read them funny  
3160 stories that I have read about prosthesis. We laugh about things that happen. I must  
3161 admit that I had a girlfriend who is counsellor come and speak to me. I said to her,  
3162 "The hardest thing is that I am letting the boys down. If I die earlier I feel like I failed  
3163 them". She said, "Now Belinda, you think about what you are teaching them, and  
3164 what you are showing them. These kids are seeing someone go through a difficult  
3165 time with a really positive attitude, and you couldn't give them a better gift than that".  
3166 That was really lovely and that helped the guilt thing disappear and I thought about  
3167 that a lot and I thought well that is true. My husband has been terrific. He had six

3168 months off last year to look after me. Having that time was great because he got  
3169 involved in their lives in a way that he wouldn't have had time before. Their  
3170 relationship is much better now which makes me feel a lot better, because I think I  
3171 would have worried otherwise if it had of happened quickly.

3172  
3173 *M: Reflecting on your illness. You said it hasn't been a bad thing.*  
3174

3175 B: I suppose journey comes to mind, this is a journey of self-discovery. Finding out  
3176 who I really am and how I work that has been important. Talking to the ladies in the  
3177 group, no members have faith. I keep praying that my sharing with them of how I deal  
3178 with stuff will make them want it. Somehow they might think that Belinda has  
3179 something that we don't and we want it. I would love to think that when they die they  
3180 will end up seeing me in heaven. It's easier to say that when I die nothing happens.  
3181 They will say to me we envy your faith. They see strength in me that they haven't got.  
3182 When they get news they are completely wiped out from anything from days to  
3183 weeks. And they talk about the whole journey being like a roller coaster. And they  
3184 can see the difference and I feel it is a lack of understanding of what being a  
3185 Christian is. That it is a relationship with a loving God. I have a personal relationship  
3186 with God.

3187  
3188 I send letters to some elderly ladies as part of my job and I get letters back about  
3189 how encouraged they are. The girls in the group have been good. Lots of friends that  
3190 we have had have been terrific. Work helps you to have some normal life and helps  
3191 me use my brain. I like being able to rewrite programs and it helps to pass the time. I  
3192 do quilting and cross-stitching. I love ceramics and I love making things for other  
3193 people.

3194  
3195 *M: When you wake up in the morning what things give you a peace of mind?*  
3196

3197 B: I just thank God for the fact that I have woken up, another day, the anticipation of  
3198 how he will work. The joy of knowing there are certain things that will happen gives  
3199 me hope. The fact that I can do housework and that is an achievement that I have  
3200 the energy. To me getting a load of washing on the clothes horse and seeing it dry is  
3201 a real sense of fulfilment even knowing that I can do it and have the time. Being part  
3202 of things. No matter how tired I am I look forward to Monday nights and I get excited  
3203 in seeing what's happening in people's day and all of that makes me get up and think  
3204 yes today's a good day.

3205  
3206 **Jane**  
3207

3208 *M: Please tell me how you came to find out about your breast cancer and how you*  
3209 *felt at the time.*  
3210

3211 J: I was having regular mammograms every two years and in 1994 I had a  
3212 mammogram and was asked to come back for further tests. I wasn't the least bit  
3213 worried about this, but eventually found out I had cancer. I saw a counsellor during  
3214 this time who was wonderful. She came to see me in hospital and this was most  
3215 appreciated. I was told that I had cancer in both breasts. I thought that this was such  
3216 a nuisance and that I didn't have time for this. Interestingly enough I had thought how  
3217 wonderful things were the week before. I went to see my oncologist who told me I  
3218 had to have my lymph nodes taken out and this could cause problems in my arms  
3219 like lymphodema, maybe for the rest of my life. Panic went through me. How would I  
3220 work if my arms were out of action? How come this is breast cancer? Then the doctor  
3221 asked me if I wanted a double mastectomy, or a partial, or a lumpectomy. I finally

3222 decided after a month that I would have a double mastectomy. I had the operation on  
3223 the 27<sup>th</sup> of June 1994 and the pathology tests showed that the lymph nodes were  
3224 infected with cancer too.

3225  
3226 *M: Can you please tell me if there were any major events that took place once you*  
3227 *were diagnosed with breast cancer.*

3228  
3229 J: Being in hospital was the worst week in my life. Having both breasts off, my arms  
3230 were totally paralyzed. I couldn't do a thing. There were machines on both sides of  
3231 me. There was a morphine gadget on one side to dull the pain, which was like  
3232 someone punching me repeatedly in the chest. I couldn't sit up to even cover myself.  
3233 For the first time in my life I was to know complete dependence on another human  
3234 being to help me. It was unbelievable. I will never ever live in such a state again. I  
3235 would prefer death to helplessness and I will commit suicide, if ever I have an illness  
3236 that renders me helpless. To get my arms back to normal I had to keep trying to raise  
3237 them and with exercise I gradually got them back to normal. That restored my dignity  
3238 and independence.

3239  
3240 *M: Have you resolved certain aspects in your life that up to now had not been*  
3241 *resolved?*

3242  
3243 J: I think the only aspect I can't deal with is an invitation from the opposite sex to go  
3244 out. All I can think of is I'm this freak of a woman without breasts and how do I  
3245 explain that my flat chest has two huge scars right across it. I can't solve it even  
3246 when I admit to breast cancer. I don't think it occurs to people that a woman has  
3247 actually had her breast off because of cancer, so I don't go out with the opposite sex.

3248  
3249 *M: What do you do when you feel threatened or are in pain?*

3250  
3251 J: I have gone from breast cancer, to secondary cancer and now to advanced  
3252 cancer. I am still thinking really positively and getting on with life. I am busy with  
3253 working, children, and grand children so there is not too much time to worry. The  
3254 treatment I am receiving is great. I am in no pain constantly, but occasionally and the  
3255 clinical trial I am working on is going fine. Another thing I do is to think about my  
3256 grandchildren. My grand daughter Naomi is very precious to me. Whilst my daughter  
3257 has helped me with my illness in so many ways, my grand daughter has provided me  
3258 with a different level of support. Just watching Naomi's eyes light up whenever I enter  
3259 the room and watching her run to me from the driveway, touches my heart. I love her  
3260 to death and treasure those moments with her always and when I feel that life is too  
3261 much and I would be better off dead I visualise her tiny, adorable face and know that  
3262 this pain is all worth it.

3263  
3264 *M: Are there any issues you are struggling to deal with?*

3265  
3266 J: I belong to a great support group which is really good because they are so  
3267 informative and can find out the latest reports on so many issues dealing with breast  
3268 cancer. I feel at least I know where I am heading and can face it because I have  
3269 support from family and friends. Apart from the spasm of pain I am keeping well,  
3270 walking seven kilometers a day, working an eleven-day fortnight, and whatever  
3271 tomorrow brings I am not afraid of death. I thank God that I have reached age sixty-  
3272 three.

3273  
3274 *M: Please tell me how it is when you reflect on your illness. What emotions come to*  
3275 *mind and is there a source that allows you to view your illness in a positive way?*

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J: I reflect on my illness with the knowledge that because my ex-husband was a chain smoker maybe I contracted breast cancer from passive smoking. Once can't change life and can only hope that technology makes things easier for our future generation. My ex-husband is ill and still won't give up smoking so I feel sorry for him, not myself. He can hardly walk and has emphysema. I can keep going for eighteen hours a day.

*M: When you wake up in the morning, are there certain things that enable you to attain a sense of peacefulness, or hope towards your illness?*

J: I think it is good because I am still working which means I have to get up, shower, dress up, put a face on and get to work. As a boss I am very busy and I don't have time to mope. I have always worried about everyone else and because I look after thirty-eight women I regularly encourage them to have a mammogram. I support them if help is needed. Then after work I walk which is calming. I can relax at home, which is peace at home. So when I close the front door, I really do appreciate the quietness.

*M: Is there a source, or sources in your life that has enabled you to deal with your illness in a positive way?*

J: I think the thing that has made me positive is the fact that my children are grown up and independent. I always had a fear when my children were young that if anything were to happen to me, I wouldn't be able to look after them. Now it's my grandchildren's love that I value and I love them so much. I want to be a part of their lives. I have looked after them constantly since their birth and want to be there to protect them.

*M: Please tell me about your faith journey.*

J: As a child I was very religious. I always felt that the faith I had in God would always keep me safe and I still feel it now. For anything good that happens in my life I say thank you Lord, and somehow it hasn't occurred to me that cancer is bad.

**Keely**

*M: I guess the first question I want to know is how did you come to find out about your illness? How did you feel at that time?*

K. It was purely a fluke that the lump was detected. I didn't think I was in a group, an age group that was likely to get breast cancer so I never did check myself, or anything like that.

*M. You were thirty-four?*

K. Yeah I was thirty-four. Once I knew that lump was there I let it go for a week ago and thought this is nothing it will just disappear and it didn't. So I thought I better go to the doctor and see what it is and what ever it is I want to have it removed because once I knew it was there I wanted to get rid of it. I went to my G.P and I was fortunate in having a G.P who didn't fob me off. I had a mammogram done and I also had an ultra sound performed at the same time. The mammogram didn't show anything at all which is quite common in younger women. The breast tissue is just so dense that it just doesn't show anything. But the ultra sound showed it up as clear as a bell. It was just sitting there. Then I was referred to a surgeon and he checked me out and said

3330 that I should have a biopsy. The results of that were back within a couple of hours  
3331 and I sort of knew then I don't know how that I had cancer. Something inside me said  
3332 prepare yourself. I went back to the surgeon that night at 6pm in his room. He said,  
3333 "I am afraid to say it is a malignant tumor. Do you have any questions?" And I said  
3334 only one, "Am I going to die?" He said, "No, absolutely not, you're not going to die".  
3335 That was my biggest fear that I was going to die. Because my grandmother was  
3336 terminally ill and my godmother had cancer right through her body and she was on  
3337 her last legs. And I've got two daughters who I wanted to see grow up.

3338  
3339 We went through the merry-go-round of you've got no private health insurance you  
3340 have to go on a waiting list for a public bed and all the rest of it. I mean you have just  
3341 been told you've got cancer but you still have to go on a waiting list for a public  
3342 hospital. I decided that I wouldn't wait a couple of weeks. I went to the bank the  
3343 following day and withdrew out the money booked into a hospital. I didn't want to  
3344 muck around with this. Once I knew that it was cancer I had this image in my mind of  
3345 this big sinister black horrible thing crawling through my body and I just wanted to get  
3346 it out and get rid of it. I had the surgery and it took me about eight weeks after  
3347 surgery to recover. I also had to get over that emotional upheaval of only having half  
3348 a breast, not a whole breast. That was a pretty hard time. Those first couple of  
3349 months I went through the cycle of tears, anger and frustration and all the rest of it. I  
3350 then reached a point where I thought I just can't wallow in this forever, my whole life  
3351 would be destroyed. It was then that I made the decision that I would deal with what  
3352 had happened.

3353  
3354 I resigned myself to the fact that I was going to put my life on hold for twelve months,  
3355 have further treatment and then after that I could start fresh. So I started a course of  
3356 chemotherapy for three months and I had eight weeks of radiotherapy in between. I  
3357 have had no recurrence of the cancer. They say after five years, if it doesn't come  
3358 back it isn't going to come back. I am up to four years now so I have only twelve  
3359 months to go and then I am right.

3360  
3361 *M: By the sounds of it you have been very positive!*

3362  
3363 K: The doctors and oncologists kept on saying to me, "You know positive thoughts  
3364 really do help". I guess it is a bit like some races. Like the aboriginal believe that the  
3365 pointing of the bone can kill them just as they believe that a thought can kill. I had a  
3366 lot of faith and a lot of determination that I was going to beat it.

3367  
3368 *M: Are there any major events that have taken place in your life since having cancer?*

3369  
3370 K: Well not long after I finished my treatment I tossed my job. I hated it. And I had  
3371 been there for a couple of years. I don't know if it was the breast cancer, or not, but I  
3372 think that I just thought oh stuff this. Why am I doing something that I really hate? Life  
3373 is too short. And I didn't have another job to go to and I said I've had enough, I'm out  
3374 of here and I quit my job. At the same time my husband had just resigned and taken  
3375 out his long service leave so we went out and bought two tickets to Greece and we  
3376 went overseas for a holiday. Just like that and that is something I never would have  
3377 done. I was always a planner and you have to think things through and always have  
3378 a contingency plan for stuff and I am not like that any more. Now I tend to feel if I am  
3379 going to do something I'm just going to go out and do it. I am going to enjoy what I  
3380 am doing, enjoy my life, enjoy my kids. So it has really turned my life around in that  
3381 way. I enjoy my life a lot more now. I have a different outlook. There are more  
3382 important things to worry about than whether your mortgage is paid off. It's not  
3383 important. When we bought this house we had quite a large mortgage. We could

3384 have paid off a lot more of it, but we chose not to. We chose to keep the cash and we  
3385 brought a new car and had a holiday. I figure whether I pay my house off in twenty  
3386 years or thirty years, it doesn't really matter. And if worst come to worst and I lose my  
3387 house and I have to live in a caravan, big deal. I still have my husband and I've got  
3388 my kids.

3389  
3390 *M: Would you have felt that way before?*

3391  
3392 K: No definitely not. One of the key factors that trigged my divorce in my first  
3393 marriage was that I was always paranoid. We gotta have money and we gotta have  
3394 this done and that done and we have to pay off our house. And my ex-husband is  
3395 very much like I am now. He is very laid back and doesn't worry. And now here I am  
3396 a complete reversal because it really isn't important. You know sure it's nice to have  
3397 goals and get things done, but at the end of the day there are more important things.

3398  
3399 There was another event that took place. I was diagnosed in the March and I was  
3400 turning thirty-four in the following June. My husband and I had decided that we were  
3401 going to try for another child. I had two daughters from the previous marriage but we  
3402 didn't have any from this one. Well of course with the cancer coming on a couple  
3403 months earlier that put everything in disorder. So while we were over in Greece we  
3404 decided that yep that's it, now that the treatment is over lets start trying. We tried for  
3405 eighteen months before we found out that we couldn't have kids. It was then that we  
3406 actually found out that my husband was infertile. He actually had a 0 sperm count.  
3407 There was just nothing there what's so ever. And we thought now where do we go?  
3408 Coming to terms with the fact that we weren't going to have children was also  
3409 difficult. If I haven't of had the cancer it may have been the case that I would have  
3410 continued to try. But, bearing in mind all we had been through in the past couple of  
3411 years we just thought there has to be a time where you stop all of this and you just  
3412 learn to accept things. Whether it be cancer, or infertility, or a death, or whatever, it  
3413 is just part of what God deals you, it is the hand you're dealt with.

3414  
3415 *M: If you say accept and I think that's the major word here. You have to accept*

3416  
3417 K: Well you can't change it. I mean there is no way I can just go out and replace my  
3418 breast. Sure I can go out and have surgery done, but I am still going to have a scar  
3419 and it is not putting me back the way I was so what's the point. To me the only thing  
3420 you can do is accept it. I am not saying that it was an easy journey because it  
3421 certainly wasn't, but in the long run you're only going to end up bitter and twisted if  
3422 you keep on asking why? No-one is going to give you the answer; there is no answer  
3423 as to why. Instead I look at it more that it was like blessing, it was a case of being told  
3424 to change my lifestyle. Look at what you have got rather than what you could have,  
3425 or might have and just accept what's there.

3426  
3427 *M: Were there certain things that helped you to cope with cancer?*

3428  
3429 K: My new job really helped. I always think that anyone that has cancer should do  
3430 some time of work, whether it be part time, or job share. Otherwise the only thing that  
3431 you have in your life is cancer and treatment. Whilst I was having treatment I worked  
3432 for a few days and that helped. Another thing is that I didn't have the support of other  
3433 women who were going through it. I attend a support group now and feel it is  
3434 important to give something back.

3435  
3436 *M: During times when you feel threatened or in pain, what do you do?*

3437

3438 K: I go out in my garden. My garden um and this is going to sound really stupid but I  
3439 feel more at peace in my garden on my own, just tending to plants and I have a little  
3440 green house down there were I actually grow stuff from cuttings. And I get so much  
3441 enjoyment at being able to take a twig and turn it into a whole plant and then give  
3442 them to friends and family.

3443  
3444 *M: Was it always like that?*

3445  
3446 K: No. I never used to be a gardener. Couldn't do anything. When I got breast cancer  
3447 I just found I needed an outlet, somewhere to go, some sort of therapy other than  
3448 basket weaving or something. And I just sort of started pottering. My dad was a  
3449 gardener and I just started pottering and I started to develop this love of it. And when  
3450 I could see that things were growing, I got a real satisfaction out of it and I got more  
3451 and more in it. I can come home and have a really bad day at work and I will go  
3452 straight out in the garden. And I'll just go out there. Even if I just walk around, or pull  
3453 out a few weeds, or trim the roses, or whatever and come back in and before I know  
3454 it, like an hour or an hour and a half has gone and I will come back just so calm and  
3455 relaxed and it is wonderful. Because it doesn't cost me anything apart from what I  
3456 spend at the nursery, but it doesn't cost me anything. It's not hurting me. It's not like I  
3457 am smoking or drinking or anything like that so it is not having any bad effects on me.  
3458 Um and everyone gets the enjoyment out of it by having a nice garden to look at.  
3459 That's my little sanctuary out there.

3460  
3461 *M: Do you do anything else? I mean is that the only thing that you do?*

3462  
3463 K: No I sew. I make about sixty per cent of my own clothes. I made all the drapes and  
3464 curtains in the house and I do it for other people as well. I've always been a sewer. I  
3465 like doing things with my hands. I can't sit still. This is the longest I've sat. Even when  
3466 I go on holidays I am always on the go I always have to have something to do. Winter  
3467 nights and days when I can't get out and do something I will be inside doing  
3468 something, I'll be painting walls or sewing or doing something to keep myself  
3469 occupied.

3470  
3471 *M: O.k. Is there a time in the past weeks that you've encountered that you have felt*  
3472 *really good about yourself?*

3473  
3474 K: Yeah actually we were talking about this on Friday night at our group meeting. Um  
3475 I was sitting at work and I have a very hectic job and the first time in months I had a  
3476 clear desk, I had everything up to date and I just looked up out of the office window  
3477 and it was magnificent outside. It was a most beautiful day and I just got up from my  
3478 desk and walked outside and stood in the sunshine for about 10mins and just  
3479 enjoyed it. And I thought I am really happy with my life. I have a fantastic job now. I  
3480 love my job, I've got a nice home, my husband and our relationship is just terrific at  
3481 the moment.

3482  
3483 *M: So when you're in the garden can you view your illness in a positive way?*

3484  
3485 K: Absolutely. I look at things out there and you go out and you find a plant that has  
3486 been trampled. Next door's neighbour's cat has jumped over the fence line, or  
3487 something like that. I get really angry. But then I think it will re-grow. I'll either trim  
3488 some cuttings and grow some more or I can fix, or if it is a total loss I'll pitch it out and  
3489 grow something else.

3490

3491 *M: So you must get a lot of satisfaction when you see anything that appears dead*  
3492 *and you give it a bit of tender, love and care and it's kind of shooting up.*

3493  
3494 K: Yeah one of the things I have done in my garden is I go to nurseries and I buy all  
3495 these plants that are sick. I bring them home and I trim them back and give them a  
3496 good feed and a bit of 'TLC' and I get such a thrill when it grows. I always have a  
3497 conscious thought go through my mind that this plant started off like me. Like me it is  
3498 broken, patched up and is now as good as new. So my garden is my sanctuary. I feel  
3499 close to people that I have lost like my Godmother, my grandmother and my  
3500 grandfather who were all great lovers of the garden. It is almost like you have your  
3501 own little spirit world happening out there and you've got something spiritual. Some  
3502 people go to church and light a candle, for me I go out in the garden.

3503  
3504 *M: And your father is he still alive?*

3505  
3506 K: Yes.

3507  
3508 *M: How does he feel because he is a gardener?*

3509  
3510 K: Well he is what I call an impatient gardener. He has an acre of gardens but he has  
3511 to buy the biggest and the best plants in the nurseries. I mean he has got the income  
3512 that he can do that. And I say, "Why don't you just try growing things from seed and  
3513 getting the enjoyment". But he tells me he wants an instant result.

3514  
3515 *M: Have you never had that relationship with him before?*

3516  
3517 K: I had a shocking relationship with my father, always through childhood. He was  
3518 never there. His idea of being a father was go to work and provide, put a roof over  
3519 your head and if you needed anything throw money at it. That's his way of fixing  
3520 things. Throw money at it that will fix it. Growing up I didn't want that. I just wanted to  
3521 spend time with my dad. Just have him around. Do all the normal things that what I  
3522 felt a dad should be involved in. But no if I was feeling down or upset, or whatever,  
3523 he would say here is twenty dollars go out and buy something pretty and cheer  
3524 yourself up. When I turned eighteen he took me to a car yard and he said pick  
3525 whichever car you want and I will buy it for you. I got married he brought me a block  
3526 of land. He was a builder he built my house. When I was first diagnosed with cancer  
3527 and I rang mum and dad and told them to come over. When I told my parents, my  
3528 dad started crying and he was a wreck, he just crumbled and he flawed me and he  
3529 said, "I don't care what it costs. We will get you the best treatment, the best  
3530 specialists that there are, whatever it takes". And I said, "Will you shut up and listen  
3531 to me for five minutes, will you just shut up. I don't want your money I have a doctor,  
3532 I've got treatment in place, I've paid for the hospital I don't want you money". I  
3533 sensed he didn't know what to do.

3534  
3535 *M: So was there ever like a turn around where you knew in his own little way he was*  
3536 *making some kind of effort to breach that gap? Is the garden something?*

3537  
3538 K: Yes we have the garden now. We have that, we never ever had that before. Now I  
3539 just enjoy it so much. And it has taken thirty-eight years to finally say I can spend  
3540 time with my father.

3541  
3542 *M: This is the last question and it's about your faith journey and we have briefly*  
3543 *touched on it. You said early on that you accept God's cards whatever you're dealt*

3544 *with you're dealt with. But, did you find throughout your illness that you had any type*  
3545 *of spirituality, or closeness with God?*

3546  
3547 K: I've never followed conventional religion even though I was baptised and went to  
3548 Sunday school, but I have never been a regular churchgoer and I have had faith  
3549 there. And I had an experience when I was hospital that made me believe that I was  
3550 being looked after, whether it be God, or a guardian angel or whatever, it gave me a  
3551 real sense of security, a sense of someone looking out for me. I was actually asleep  
3552 in the hospital bed and it was about three days after my surgery. It was in the middle  
3553 of the night and I woke to this sensation of a cool hand on my forehead and I thought  
3554 it's the bloody nurse again checking my blood pressure because they are always  
3555 coming to check up on me. And I felt this coolness on my forehead and I opened my  
3556 eyes and looked to where I expected the person to be and there was no-one there  
3557 and I turned my head to the other side and there was no-one there, but I could sort of  
3558 get the image of light. And just for a split second I saw an image of my uncle who had  
3559 passed away many many years earlier. And I saw his face and we were really close  
3560 and I saw his face and he looked really well and happy and it was just this golden,  
3561 orangy light and he just looked at me for a split second with a smile on his face and  
3562 it's gone. And I thought Ted is looking after me. I had never had anything like that  
3563 before. And then the next thing that went through my mind was shit if he is dead and  
3564 I can see him then I must be dead too. And all these thoughts are going through my  
3565 mind and I thought no I am awake and I buzzed like crazy and the nurse came and I  
3566 didn't tell her anything that happened because they would stick me in a psych ward  
3567 or something. I called the nursed and realised that I was fine. It was funny I used to  
3568 think about that constantly, I still do. It gives me a feeling, it's not just God, which is  
3569 sort of an abstract thing. To me it is more personal. It's like I've got someone there  
3570 keeping an eye on me.

3571  
3572 *M: So were you able to differentiate whether you were in a dream state or whether it*  
3573 *was reality when these visions occurred?*

3574  
3575 K: Oh I was awake. And I told my doctor and he said, "It was probably the  
3576 tranquillisers you were on or something your were hallucinating", which they do. And  
3577 I thought no I was awake and I thought I don't care if you don't believe me I don't  
3578 care. I don't care if no-one believes me, but it made me feel good and it's no different  
3579 to people of different faiths that some go to church, some don't there are so many  
3580 different people that have different ways of doing things whatever gives you comfort.  
3581 Whether in conjunction with the peace I feel in the garden whether all of that has  
3582 helped me to become a better person. That's my faith.

3583  
3584 **April**

3585 A: I was first diagnoses in June 1990 and I found a lump in my breast in the shower  
3586 and I thought no it isn't there, I didn't do anything for a fortnight and didn't tell my  
3587 husband because I didn't want to worry him so I went to the local doctor and she said  
3588 you better get a mammogram done. I would have been about fifty-four. The  
3589 mammogram was a bit inconclusive, but I was referred to a breast surgeon in Box Hill  
3590 and by this time I told my husband he said why didn't you tell me. By this time I was  
3591 feeling quite shattered, quite devastated. It's an awful feeling. So I went off to see the  
3592 surgeon. He told me I would have to have a biopsy and that he would have to  
3593 operate. Within a week I was in a private hospital locally which was nice because my  
3594 husband could come up. They were very nice to me and spoke to me and said you  
3595 know what is going on.

3596

3597 After the operation I came out of the anesthetic. It was then that they told me they  
3598 had to take the breast off. I was ok. I was relieved that I was still alive and kicking  
3599 and I was fine. I was in hospital for a week and I sort of came to terms with it a little  
3600 bit and the surgeon came in every day to check up on me. They had done some  
3601 other tests and the cancer hadn't spread. I was told though that I would have to have  
3602 follow-up checks. Following this I went back to work. I was working then full time. I  
3603 felt better and I had been feeling tired and I actually felt much better within myself  
3604 and I was going to the surgeon every three months, than every six months then it got  
3605 to six years and I had had no problems at all. I was feeling fine. In 1996 we had a car  
3606 accident and I broke my ankle and after I came out of the plaster I started getting  
3607 pains down my leg. The orthopaedic surgeon said it might be just the accident you  
3608 have hurt your back. It wasn't until I had a MRI that they found cancer and they said I  
3609 had a tumor on my lumbar spine and I thought no. And that strangely enough was  
3610 more devastating than the first diagnosis. The fact that it had returned because I  
3611 suppose when you have the first lot and they said your cured and then when it  
3612 reoccurs you know it is a different ball game so I was completely shattered. So I was  
3613 back to the surgeon and he said, "You will probably have to go on radiotherapy on go  
3614 on tamoxifen, hormone therapy". So then I went to see a radiation oncologist at Peter  
3615 Mac and she was excellent. I had radiotherapy and that wasn't a problem and the  
3616 pain went the tumor had shrunk so that was fine. But, I was very very depressed  
3617 and I think when I look back on it I probably had a bit of a nervous breakdown  
3618 because I wasn't interested in anything and everything seemed distant and far away  
3619 and I couldn't snap out of it. The oncologist realised this and she recommended that I  
3620 see a counsellor. I saw her once and that helped because I think she made me talk  
3621 about it and get it out of my system. I actually broke down and cried which I hadn't  
3622 done which I think was a good thing and after that I started picking myself up.

3623  
3624 I was fine till the middle of 1998. I had some pain around my ribs and I told the  
3625 oncologist about it and they found out I had another tumor high up in my spine. So I  
3626 had radiotherapy and the pain went away. I then had so more tests done and they  
3627 found I had some spots on the liver. I had to have chemotherapy and I don't like it. I  
3628 felt quite ill and I got shingles and I got a face rash and my hair dropped out so I think  
3629 I was feeling the lowest I could go. I remember one day I went to see my medical  
3630 oncologist. I went into her room and I had this red face with this rash and no hair. I  
3631 had a turban on and she said "no wonder you feel so miserable". She sent me off to  
3632 a dermatologist who gave me some antibiotics and some cream so that fixed that up  
3633 and we plodded along with the chemo and you would feel reasonable for about a  
3634 week and then have chemo and feel horrible.

3635  
3636 In 1998 it seemed to keep things under control. Things didn't actually go away but it  
3637 seemed fairly stable so we trundled along and I was working three days a week,  
3638 which was fine. They were very good at work and they were extremely supportive  
3639 and if I had to have treatment they would say you just go and do it. I am a librarian. I  
3640 ended up working at the electricity supply association so and did some work on how  
3641 it effects the Electro magnetic field from the power lines so that was very interesting.  
3642 Work friends were lovely. It is a very small place and there are only about eight of us  
3643 in the office. I knew them very well and they were all extremely supportive and I  
3644 remember the day I went back after I had been feeling so low and depressed and  
3645 that was the worst bit I think and they were just so nice and offering to make me cups  
3646 of tea and fussing around. When I had the wig, I was a bit embarrassed about losing  
3647 my hair and I got this super wig and most people didn't even know it was a wig. My  
3648 own hair starting growing back and my husband said, "Look it is time to go out. Your  
3649 hair is short but it looks fine". It was quite fashionable so I got on the train thinking  
3650 everyone would be looking at me, of course no-one noticed. I walked into the office

3651 and the young ones said, "Cool, I love your hair do" and they were all so nice about  
3652 it. I was very glad about it actually, it helped a lot. Then last year I got this leg pain  
3653 and I had a MRI and it was the same spot on the lumbar spine and I had more  
3654 radiotherapy which fixed it. At the moment I see my oncologist about every six years  
3655 and I have a blood test three times a year and I have bone scans, but things seem  
3656 stable and controlled. I feel great and I have just come back from a month's holiday  
3657 in Canada and U.S.A. I have retired now. I retired at the end of last July. My husband  
3658 had been retired for a while so he was my househusband whilst I was working. He  
3659 hasn't quite woken up yet. So we are o.k.

3660

3661 *M: When they found your second cancer you said you had a nervous breakdown, but*  
3662 *when they found the subsequent cancers why were you able to cope?*

3663

3664 A: Well I think the group helped. I have been in the group for three years. I am a part  
3665 of a research group for women with secondary breast cancer. I was a bit hesitant at  
3666 first to take part because I am not a group person. I am private and I am not one that  
3667 would naturally talk in a group and bear my soul. It is not quite my style, but I would  
3668 agree to give it a go. There were two sorts of options. One was like meditation and  
3669 the other was the group that would last for a year and I got selected for the group and  
3670 I thought that it is a big commitment and I thought a whole year once a week seemed  
3671 a big commitment to make. I think we were all the same and we were all wondering  
3672 what we were doing, but after a while I found it so helpful, just the support. You see  
3673 you can talk to your friends and they are good and supportive but unless they have  
3674 been through cancer you don't really understand. And here were these other women  
3675 who felt the same and also we could swap how we had handled it and things. Even  
3676 simple things like an upset tummy or nauseous you could say I tried such a thing. It  
3677 was practically and emotionally helpful. We are lucky because our group is  
3678 professionally run. It is a very interesting group. And the only thing that really did  
3679 worry me when I joined was what happens when people die? The first time it  
3680 happened it was hard but somehow you cope. You sort of accept. At the moment I  
3681 have been going for three years and there are only two of us left from the original  
3682 eight and we have lost eleven members of the group. It is hard but somehow the  
3683 benefits of being in the group out weigh that. I didn't think I could cope with that I was  
3684 quite amazed at myself. We have been to funerals.

3685

3686 *M: Have you always been a person that copes with things?*

3687

3688 A: Probably I suspect, but so do other members in the group. It is very interesting.  
3689 We have also become quite close with people's families like husbands and so on. My  
3690 husband knows other people in the group. We have gone out a few times. During  
3691 Christmas time we have a lunch. We try to get to breast cancer seminars and then  
3692 we report back to the group. There is a lot of information that goes on and a few of us  
3693 have the Internet and if we find things and share it with the group, or books. We  
3694 remember people's birthdays. We have a group Kitty and we buy presents for people  
3695 and cards and we go out now and then and we also ring each other so there is a  
3696 close net going on.

3697

3698 *M: What about your friends, were they supportive?*

3699

3700 A: Most of them yes. I have one friend whose sister in law died with breast cancer so  
3701 she could identify with my problem. Most are very supportive but it is strange and  
3702 most of group friends have said this is that sometimes you think the friends who will  
3703 be most supportive perhaps can't cope with it that well. And I have a couple who are  
3704 supportive but don't ring me that much and I think it is because they can't face it and

3705 perhaps don't know what to say. So sometimes you get a little disappointed with  
3706 people because sometimes you think the people you would be supportive aren't.

3707

3708 *M: In terms of support how do they give you that support?*

3709

3710 A: They will ring. We keep in touch and we share different things together.  
3711 Neighbours have been wonderful. They will pop in and have a coffee. When I wasn't  
3712 well my next-door neighbour would pop in and I knew that she would be there for  
3713 you. Cancer can be a very isolating thing and you can feel very alone with it. I did at  
3714 first and I think initially I wasn't given enough information about it and where to go  
3715 and a lot of the things I had to find out for myself. Since being in the group and  
3716 sharing things you become more knowledgeable and you feel in control. I don't  
3717 understand a lot of it as I am not scientifically minded but I know a lot more about  
3718 treatment and things than I did before and I feel at least I can ask the oncologist  
3719 intelligent questions. I think you should learn a bit about it. It is no use going along  
3720 with it and not knowing what's happening which is what a lot of people might do. I  
3721 have made so many friends from the support group. The husbands of wives who  
3722 have died have come to have coffee with the group. They seem to want to do it. We  
3723 meet at the hospital and we always have a coffee in the cafeteria afterwards. A  
3724 couple of husbands came which was nice so they derived some comfort from the  
3725 group. We understood their wives. One of the husbands was left with three children  
3726 and one girl in the group was very good to him. She still keeps in touch with him,  
3727 which is nice. It has sort of gone beyond the group. We feel a bit vulnerable the other  
3728 girl and myself who are the two remaining out of the original eleven, but we just sort  
3729 of laugh about it and say we have to keep going.

3730

3731 *M: Were there any major events that took place after your diagnosis?*

3732

3733 A: The car accident was pretty traumatic. I was ok until I started getting the pain in  
3734 my legs and the cancer came back. It was quite shattering after six years. The  
3735 depression lasted over a month. I have never felt that way before. It was a peculiar  
3736 feeling. The counsellor helped me. Time helped me to get over the break down and  
3737 coming to terms with it. I really felt that I had to make some sort of effort. Oh yes  
3738 there was another positive thing because for a while one of the nurses from the  
3739 hospital came once a week for a home visit. She was a character and she is a real  
3740 up front lady and she wouldn't take nonsense from anyone. And she would see me  
3741 once a week and have a cup of tea with us and see how I was and of course I am  
3742 sitting there like a blob. And one day she said, "Oh well if you are going to be like this  
3743 for the rest of your life". This was like a turning point and I thought golly how dare she  
3744 say that to me. I realised afterwards it was to try and get a reaction from me and it  
3745 worked. I thought I am not going to feel like this and I just seemed to pick up. The  
3746 counselling also helped. Then I got back to work because work helped to restore  
3747 some normality because you feel abnormal. I think this is the big thing. You are no  
3748 longer April, your April with cancer and it can make you feel your not normal. I have  
3749 never kept it a great secret and I don't mind people knowing but you do have this  
3750 feeling that you're different from other people but of course life goes on. I have  
3751 always thanked her for that because she did help me with that.

3752

3753 *M: You said a lot of people think that these cancer groups are doom and gloom and*  
3754 *they aren't really. We do have a laugh in our group.*

3755

3756 A: Yeah that's true and I think we have all found this in the group. Having the cancer  
3757 does have a positive side in that it makes you appreciate life. I suppose you're aware  
3758 that your life is limited. I think because you know you have a terminal illness you feel

3759 your mortality. Nobody likes to think about death and dying but you really have to  
3760 face up to it and knowing that your time is limited you do things. In the past you may  
3761 have put things off but cancer makes you think of the moment. Travelling is one  
3762 thing. When I had the first diagnosis in 1990 we didn't go overseas. We have always  
3763 had nice holidays around Australia. But I think this overseas trip was different. We  
3764 decided that we would go to Canada. I was a bit hesitant because I couldn't get the  
3765 full travel insurance. They won't give it to you if you have a terminal illness. I thought  
3766 both Canada and America are expensive if you get sick so I thought what do. I got a  
3767 letter from the oncologist that outlined my history and she said if anything happens to  
3768 give this letter to the doctor and they can ring me and I will talk to them. She gave me  
3769 morphine and panadene fort. So I was nervous but I was glad I did it. I got more out  
3770 of travelling after my diagnosis. Everything is sort of heightened. I think you feel  
3771 things more and you appreciate things more and when I was seeing things like the  
3772 Rockies and Niagara Falls and San Francisco and all this lovely scenery I  
3773 appreciated it even more.

3774  
3775 *M: What about doing things around the house do you enjoy that more?*

3776  
3777 A: Yes that is true. I came home and the daffodils were out and I came back to my  
3778 house and I thought it was nice. On sat night we had drinks with the neighbours and I  
3779 thought gee that's so nice. I think you do perhaps take things for granted when  
3780 you're not sick. I take nothing for granted now. It is a definite plus that.

3781  
3782 *M: Many women I have spoken to say that after cancer they tend to become a little*  
3783 *bit more selfish.*

3784  
3785 A: I think you have to to some extent. If there is something I don't want to do I won't  
3786 do it. One time I might have gone out of politeness and I think no my time is too  
3787 precious. I am a bit more selective. I think it is a feeling that your time is precious.

3788  
3789 *M: Were there any aspects that you needed to resolve in your life after the onset with*  
3790 *breast cancer?*

3791  
3792 A: Yeah that is difficult. We don't have children so you tend to get a bit selfish.  
3793 Perhaps it made me realise that and helped me be more understanding of other  
3794 people. I find I try to help other people more than I had previously done where as I  
3795 think I was a rather selfish person. Helping them by being there for them. I do feel I  
3796 am a better person for it and perhaps I am a bit more tolerant and try to see the other  
3797 person's point of view. I try not to be so involved in my self so much. We have a  
3798 happy marriage. In fact cancer has strengthened our marriage and he has had to  
3799 face up to a lot and it can't be easy for him. He has seen me sick and not well and  
3800 feeling down and I think he appreciates our marriage perhaps more than he did  
3801 before. Cancer helps you get your priorities right. I met someone nice through work  
3802 and his wife had lymphoma and I would try to be friendly and the four of us have  
3803 become good friends and he and my husband like Jazz and he said it makes you get  
3804 your priorities right. I think cancer helps put things in perspective and enables you to  
3805 enjoy life. I try to enjoy each day and I try to get something nice out of each day. I  
3806 think I enjoy my days more now than before I was diagnosed because I am more  
3807 aware of living I think.

3808  
3809 *M: When you feel threatened or in pain what do you do?*

3810  
3811 A: I do try to relax. We have been lucky with the group. We have on occasions had  
3812 someone visit to teach us about relaxation techniques and I don't use it all the time

3813 but if I am feeling stressed or depressed I do try to do the breathing and the  
3814 relaxation and I find that helps a lot. I like my garden that is good therapy. Yes I can  
3815 forget about anything. My mother liked her garden in England. A few years ago we  
3816 had all the paving done and we had the garden landscaped and I really took a great  
3817 interest in it. I wasn't quite so interested in it before my cancer. We didn't really have  
3818 a nice garden it was hard work. It is creative and good therapy. I really like seeing  
3819 things grow. Beautiful things...I do notice the seasons more. I went and took photos  
3820 of the beautiful things in my life. I think I am more aware of things like nature. We  
3821 quite like walking and I like music and that I like and I like the theatre and the ballet. I  
3822 go to plays with friends of mine and meet them for lunch and we share things.

3823  
3824 *M: Was there a time in the last three weeks where you felt good about yourself?*  
3825

3826 A: Well the trip did us the world of good. We were away for a month. The group is  
3827 good because the co-coordinator is a psychiatrist but also into palliative care. He is a  
3828 professor and it is great to have free medical advice and free counselling. One  
3829 woman is having a hard time with her son who is on drugs and they have given her  
3830 good advice. This all impinges on your well-being if you have family problem. Women  
3831 bring their worries to the group and they are given good advice. When I was on the  
3832 trip I felt normal and most people didn't know I had a problem because you are out of  
3833 your environment, apart from relations and friends who knew. I think it took me out of  
3834 myself there was so much to see and do and I was busy enjoying all the sites so I  
3835 had no time to think of me. Sometimes you can dwell on your illness.

3836  
3837 *M: Please tell me about your views on body image and sexuality.*  
3838

3839 A: I must admit I did feel when I had the breast removed that I was embarrassed  
3840 about it. I have a very supportive husband and this helped. But I sort of came to  
3841 terms with it. I am still me. But do you know what I think was the worst losing my hair  
3842 with the chemo because hair is such a personal feminine thing. That worried me  
3843 more than anything. The wig helped and it was so life like that a lot of people didn't  
3844 know and I felt comfortable with that and I had some little turbans and I would wear  
3845 those around the house. Some people can go out bald, I couldn't do that. I never had  
3846 a bad hair day it was marvellous. You just fold it up in the morning give it a wash on  
3847 the weekend and shake it out. When I was bald in bed and there was this little  
3848 baldhead on the pillow my husband would say, "My favourite alien".

3849  
3850 *M: So when you reflect on your illness, what emotions come to mind?*  
3851

3852 A: Well I think initially devastation and panic and when I found out about the  
3853 secondary diagnosis I thought I was going to die tomorrow. And I was in there doing  
3854 all the ironing and making sure everything was up to date. I am still a bit that way and  
3855 I feel there are some things that need to be in place. Yeah that awful initial feeling of  
3856 panic and I was scared and terrified at how I might die. Not the dying, the how. And I  
3857 think since talking about it and even seeing some friends die peacefully has helped.  
3858 Because most of them have died peacefully. I had this awful fear of being in terrible  
3859 pain and in agony and now I feel hope. I feel hopeful there are new treatments at the  
3860 time. I did read books a lot at the time. The work I was doing I was sort of indexing  
3861 stuff on cancer which helped I think because it took the mystique out of it. It did kind  
3862 of help me to face up to it. I try to go to these seminars and there is a lot of  
3863 information. The self-help group gives you hope and you sort of realise there are  
3864 people worse off than you sometimes and you see how they cope and that helps.

3865  
3866 *M: When you wake up in the morning how do you feel?*

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A: I often wake up feeling a bit worried and anxious but it soon passes. I think sometimes I feel apprehensive and I try to think of something nice and then it goes away. Positive thinking helps. Sometimes in the middle of the night I might wake up anxious and I try to think of pleasant things.

*M: My final question is has there been a faith journey in all of this?*

A: I suppose I would say I am not an atheist. I am an agnostic. I sometimes would like to have faith because I have seen some of my friends in the group who have strong faith and this helps them tremendously and in a way I sort of envied that faith. But I have come to the conclusion it is not me. I think I am a Christian and I suppose I have my own personal belief. I think God is nature. I think there is something because everything is so marvellous. I just can't accept this formal God. I think if I did it now I would do it for selfish reason just in case. I do think nature is wonderful and I see something in that. I feel that is quite spiritual seeing beautiful scenery. This makes me feel good inside. No religion hasn't helped me and I know it can but I think you have to be that way inclined anyway. Although I know a couple of people who took up religion and have found it comforting. I don't think I need it. I am quite comfortable.

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