

## CHAPTER 16

### PARENTAL BEREAVEMENT: FROM GRIEF THEORY TO A CREATIVE NONFICTION PERSPECTIVE ON GRIEVING THE DEATH OF A YOUNG ADULT CHILD FROM CANCER

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#### Abstract

*The death of a child is the most tragic of all deaths. Parental grieving is the most devastating, the longest lasting, and the most far-reaching in its effects, of all forms of grief. Much of the current literature on parental grieving has been written from a medical, sociological, psychological or anthropological perspective. Whilst contributing to scholarly understanding of the topic, the models of grief in these texts are described in academic language that is not easily accessible to bereaved parents. In addition to these academic texts, there are many published books written by grief counsellors and bereaved parents that focus on infant death, child death after illness, sudden violent death, and teenage suicide. While there are some similarities in grieving the death of a young child and an adult child, there are also many differences, just as there are differences in grieving sudden death in young adults and young adults who have died after a terminal illness. Though there are studies on sudden death in young adults, there is a paucity of information, in both academic literature and market-orientated works, on the topic of grieving the death of a young adult child from cancer. This chapter will review the existing literature on parental grieving and outline how a creative nonfiction narrative may illuminate theory with the lived experience of parents grieving the death of a young adult child from cancer.*

#### INTRODUCTION

Before the 20th century, the death of a child in Western societies was a common occurrence. Most parents had many children in the hope that at least some of them would survive. The inevitability of the death of children was regarded with the same acceptance that the death of the elderly is today (Knapp, 1986). However, parents were not left to grieve alone. Bereavement was an experience shared by the whole community (Riches & Dawson, 2000; Worden, 1982). With the introduction of vaccination, antibiotics, improved hygiene and public health systems, the diseases that had previously decimated large numbers of children were eradicated. (Knapp 1986; Kubler-Ross, 1970; Riches & Dawson, 2000; Rosof, 1994).

The post-1940s generation was the first to enjoy a healthy childhood. When these children eventually became parents, unlike their predecessors they did not

usually have any experience of childhood death (Rosof, 1994). The trend to smaller families, increased economic, medical and emotional investment in children, together with raised awareness of good parenting practice, resulted in parents assuming it was within their power to keep their children safe (Riches & Dawson, 2000, Rosof, 1994). Modern parents are generally aware of potential health problems and risks to a child, and have more ability to seek appropriate help. The idea of a child dying, therefore, is so foreign that when it occurs, the family is often thrown into crisis. A typical result is that parents blame themselves for not being more vigilant (Knapp, 1986).

Societal norms, which have been well established to deal with the death of the elderly, have not been developed to the same extent to deal with the comparatively rare event of child death (Knapp, 1986). Klass adds that in contemporary, mobile, fast-paced, consumer culture, parents are often on their own, without the anchors taken for granted by past generations that helped to place the death of children in its proper perspective. Thus, not only are modern parents often left to grieve alone, but also unrealistic expectations are placed on them in how and when they express their grief (1999). To grieve openly in a society that expects this kind of restraint, the bereaved run the risk of rejection (Tarelbaum, 1981).

The lack of familiarity with child death in the wider community is shown by the frequency with which parents report that friends and colleagues, in trying to offer sympathy, often respond with comments such as: "I know how you feel. I lost my old dad last year – he was 92" (Grinyer, 2002, p. 161). Even worse, says Grinyer, are comments about the death of a beloved pet, which, the commentators imply, qualify them to empathise, or remarks that the parents are lucky in having other children, or can have more.

A child's death preceding that of the parents is regarded as unnatural, as it subverts the natural order (Davies, 2004). Parents lose not only their child but also all their child represents, such as a future together and descendants. Life, as they assumed it would be, ends with the child's death and the role of parent changes to that of bereaved parent (Talbot, 2002).

This chapter examines how changing theories of grief have opened a space where bereaved parents may write their own story of grief. It is divided into the following sections: traditional models of grief; grieving the death of a child; grieving the death of a young adult child from cancer; a new model of grief; a death denying culture; reading and writing about grief; the language of grief. Finally, it will outline the benefits to reader and writer of a creative nonfiction narrative on grieving the death of a young adult child from cancer.

A search was made of nursing, health sciences, sociology and psychology databases, Cinahl, Medline and SocIndex, using the key words, *parental bereavement, theories of grief, cancer, child death and adult child death*. The reference lists of studies and books thus accessed identified key authors and research. An internet search on creative nonfiction led to the online journal *Creative Nonfiction* with links to book lists on and about the genre.

## TRADITIONAL MODELS OF GRIEF

Bereavement is the state of having lost a loved one; grief is the feeling associated with that loss, and mourning is the way in which grief is expressed according to cultural norms (Davies, 2004).

Psychiatrists developed the traditional models of grief used by Western health professionals for most of the twentieth century. Freud developed the first model in 1917, based on the theory that grieving involved a process of detaching from the deceased person. Recovery took place when the detachment was complete and the bereaved person could then move on to form new attachments (Freud, 1961). This theory was developed further by Bowlby, who classified grief into three stages: searching, despair and reorganisation (Bowlby, 1961). Searching behaviour as a component of early grieving has also been noted in some animals and birds whose mates have died. Worden (1982, p. 8) refers to Darwin's 1872 description of the ways animals express sorrow, and to Lorenz's (1963) study where geese were observed flying for miles, calling and searching.

After a study, with Parkes, of 22 widows, Bowlby added another stage: numbness (Bowlby & Parkes, 1970). Kubler-Ross's (1970) work with the terminally ill and their families led to identification of five stages of grieving: denial, anger, bargaining, depression and acceptance. Worden (1982) developed a four-task model: accepting the reality of the loss; working through the pain of grief; adjusting to life without the deceased and withdrawing emotional energy, and finally, re-investing in another relationship.

All these models centred on the belief that the resolution of grief lay in detachment from the deceased. However, as Walter (1996) points out, while the models may be useful in working with grieving spouses or relatives, they are not appropriate for bereaved parents, for whom it is impossible to detach and re-invest.

## GRIEVING THE DEATH OF A CHILD

The parent-child bond is arguably the strongest bond there is; the death of a child is often referred to as the ultimate loss (Gorer, 1965; Klass, Silverman & Nickman, 1996; Kubler-Ross, 1997). "When you lose your child there are no precedents. Nothing prepares you for your loss, or for the intensity of your grief... grief for a child is wrenching and disabling. It hits harder and lasts longer than anyone anticipates" (Rosof, 1994, p. 5). Finkbeiner's American study of 30 bereaved parents sums up the emotional injury suffered on the death of one's child as being equivalent to the kind of physical injury that would necessitate a stay in an Intensive Care Unit. As one parent put it: "If children are part of parents, they are not arms or legs but bones and breath" (Finkbeiner, 1998, p. 238). When Freud's daughter Sophie died, the reality of his grief was vastly different from that proposed in his theoretical model. In a condolence letter to a friend, nine years after Sophie's death, he wrote:

*Although we know that after such a loss the acute stage of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. Actually, this is how it should be. It is the only way of perpetuating that love which we do not wish to relinquish (Freud, 1961, p. 239.)*

Most of us experience the death of a parent or grandparent and the loss of the past it brings, but when a child dies, we lose part of our future (Schiff, 1977; Staudacher, 1987). Rosof expresses it thus: "Your child is woven through the tapestry of your future, an integral part of the design. When death rips your child from the tapestry, the design is changed, damaged beyond repair" (1994, p. 18). Duder, whose daughter died of heart failure in 1992 at the age of 24, writes in the foreword to Gatenby's New Zealand study of bereaved parents:

*This grief is not like that for a spouse, a partner, a parent, a grandparent, a sibling, a relative, a colleague, a life-long friend. This grief is different. Yes, it is different... It's a club not one of us chose to join or wants to belong to. The membership is for life; we cannot resign, take leave of absence, or escape by moving to another city or country. It's a paid-up life sentence, inescapable (Duder, 1998, p. 7).*

Many bereaved parents echo this life-long aspect of grieving the death of a child (Levine, 2004; Tonkin, 2006). Edmond wrote of trying to learn a new way of being that would accommodate her young adult daughter's death while accepting she would never be reconciled to it: "Nothing ever changed my repudiation of the death of someone so precious to me and so young" (1991, p. 237).

In bereavement literature there is agreement that the death of a child is almost beyond the parents' endurance (Gorer, 1965; Klass, Silverman & Nickman, 1996; Kubler-Ross, 1997; Riches & Dawson, 2000). Staudacher (1987) asserts that the younger the child the greater the sense of loss, whereas Gorer argues that the death of an adult child has a greater impact on parents (1965). Dean et al. point out that although there appears to be no conclusive evidence of this, several studies (Arbuckle & de Vries, 1995; Cacace & Williamson, 1996; Goodman et al. 1991; Leshner & Bergey, 1988; Levav, 1982; Miles, 1985; Sanders, 1979; Seguin, League & Kiely, 1995; Shanfield & Swain, 1984) have shown that parents grieving the death of an adult child can suffer depression and ill health for many years. It is an area therefore, that begs further investigation.

## **GRIEVING THE DEATH OF A YOUNG ADULT CHILD FROM CANCER**

Although many studies have been conducted on parental grieving, most of these are on the effects of infant death (Lang & Gottlieb, 1993; Murray & Terry, 1999), child death (Hazzard, Weston, & Guiterres, 1992; Laakso & Paunonen-Ilmonen, 2002; McIntosh, Silver & Wortman, 1993), child death from cancer (Tonkin,

2006), adolescent death (Davies, 2001), adolescent suicide (Hoekstra-Weebers et al., 1991; Seguin, League & Kiely, 1995) and sudden violent death (Levav et al., 1988). According to Gorer, the death of an adult child is the hardest of all to endure and such grief lasts longer than all other forms (1965). The studies that exist on grieving the death of an adult child focus on suicide and sudden violent death. The literature is sparse on grieving the death of a young adult child from cancer.

Blank's (1998) self-help book is written from the perspective of a mother grieving the death from cancer of her 39-year-old daughter and the effect of adult child death on elderly parents. Cacace and Williamson's (1996) study examines adult child death and the effect on older parents. Dean et al. (2005) describe parents' experiences in coping with the death of an adult child from cancer. However, Grinyer's studies are the only ones that focus specifically on the young adult (18 to 25) group. Her 2002 study examines parental stress in caring for young adults with cancer, with particular regard to the additional problems resulting from the life stage specific to this age group. Her 2003 study looks at young adults with cancer and their parents' interactions with health care professionals. Her 2006 study examines the impact on mothers' health of caring for young adults with cancer.

It is surprising that grieving the death of a young adult child from cancer has been so little researched, as with such a death the parents not only have to endure the grief of losing their child, they have also had to suffer the indescribable pain of hearing a terminal diagnosis, had their hopes raised and then dashed as treatment options failed, and then watched their child suffer, waste away and die. As Rosof says: "A terminal diagnosis slashes through the tapestry of our future, tears out the warp where their design was to emerge" (1994, p. 177).

Knapp reports in his sociological study of 155 bereaved parents that the shock and disbelief parents feel on the news of their child's sudden death is the same shock parents feel when they first hear the terminal diagnosis, and the illusion that cancer only happens to other people is shattered. They then suffer months or years of denial and anticipatory grieving before the death of their child occurs (1986). Cacace and Williamson report personal disruption, unnatural survivorship, isolation, reminders and coping strategies as recurring themes in their study of bereaved parents, whose adult child had died of cancer. The avoidance of the topic by friends was an exacerbating factor in the parents' distress (Cacace & Williamson, 1996).

Dean et al., in their Canadian study (2005), based on interviews with parents of 10 adult children who had died of cancer, note that where death from cancer has been studied, the focus has been on psychological outcomes (Arbuckle & de Vries, 1995; Grinyer, 2001; Levav, 1982; Leshner & Bergey, 1988). Whilst contributing to scholarly discourse the research to date does not elucidate how it feels for parents to live through, what Knapp refers to as, "the ultimate tragedy" (1986, p. 14). Dean et al. (2005), discuss the parents' difficulty in accepting a terminal diagnosis and the common complaint that health professionals either did not acknowledge them, or made inappropriate remarks. Davies (2004) draws attention to the fact that

although health professionals have a critical role in supporting grieving parents, this does not appear to reflect the actual experience of many bereaved parents.

In Grinyer's English study of the impact on mothers' health in caring for young adults with cancer, she found a contributing factor to ill-health was that cancer is so rare in the 18 to 25 age group, that when it does occur, the family feels extremely isolated (2006a). The support networks available for young children with cancer and their families, for example, The Child Cancer Foundation, and Can Teen in Australasia, do not exist to the same extent for the older age group. Another factor was that mothers ignored their own health while focusing all their energy on supporting their young adult child. Some mothers were prescribed anti-depressants for what Grinyer describes as a rational response to an unacceptable situation.

On the subject of ill health in the bereaved, Virginia Ironside, a British journalist, cites Henry Maudsley, a Victorian psychologist, who wrote: "Sorrow that has no vent for tears makes other organs weep" (1996, p. 13). The American writer, Didion, says the bereaved "clogged their sinuses with unshed tears and ended up in otolaryngologists' offices with obscure ear infections" (2006, p. 47). Rosof confirms this in discussing the growing body of research (Spratt & Denney, 1991) that examines how stress, particularly grief, depletes the immune system (Rosof, 1994, p. 246). Other studies on this topic include Olf (1999), Cohen and Rabin (1998), Kaprio, Koskenvuo and Rita (1987), and Levav (1982). Schnell (2000) describes how every time she began to talk about her dead child she started coughing so hard she bruised her ribs. At first blaming it on a cold, she came to realise she was "simply choking on words" (p. 5).

## **A NEW MODEL OF GRIEF**

Since the 1980s, a new model of parental bereavement has been developing, based on studies of bereaved parents and the ways in which they maintain bonds with their dead children, through keeping possessions, sharing stories, establishing rituals and memorials and talking about and to the deceased (Davies, 2004; Klass, 1993a, 1993b; Rosenblatt, 2000; Talbot, 2002). The parents in these studies showed that it was only through continuing bonds that they were able to go on with their lives without their children as a physical presence. Rosof describes this process as "simultaneously building a life in which the child does not live and keeping the child alive in your heart" (1994, p. 48). This is an enormous shift in attitude from Worden's assertion that keeping the deceased's possessions or room intact was a denial of reality and a sign of being stuck in pathological grief (1982).

Daher, an American psychologist (2003), outlines the stages he went through after the suicide of his 22-year-old son as: the crying; the despair; the anger; the longing; the remembering; the forgetting; the loss; the attachment. Attachment as the final stage of grief is confirmed by parents in the international self-help organisation for bereaved parents, The Compassionate Friends, who say that the resolution of their grief did not include breaking the bond with their child, but of "integrating the child's life into the

parents' life" (The Compassionate Friends, as cited in Klass, Silverman & Nickman, 1996, p. 210). The ways in which this integration takes place is what Edwards refers to in the biography of her dead son, as "post-death parenting" (2006, p. 124).

Edmond wrote of the need her family had in keeping alive her dead daughter's qualities: "Not as someone we remembered and talked about... but as a presence in the new things we did" (1991, p. 236). In trying to accommodate this view, Edmond said:

*I had to enlarge my understanding of the world to make room for it, so that living could go on with me in it, and Rachel, and her death. She herself, all my memories of her, and the fact of her short life, her loss, must become part of everything I thought and did (p. 236).*

Finkbeiner (1998) echoes these feelings in her case studies of parents whose young adult children had died from five to twenty-five years earlier. Dismissing traditional theories of "stages", she discusses the various ways in which parents can come to terms with their loss and integrate the child's trajectory into their own lives, reiterating that when children die the bond does not break: "I think the parents insert the children into their lives and continue living, one person now, parent-and-child" (p. 244).

## A DEATH DENYING CULTURE

Continuing bonds are discussed in Walter's biographical model of grief (1996). Drawing on sociological studies and his own experience of bereavement, he states the importance of constructing a biography of the deceased through shared conversations, so their memory may be woven into the lives of those who loved them. However, as Riches and Dawson (2000) point out, many people are averse to engaging in conversations about the dead.

This unwillingness to listen to the bereaved is symptomatic of what Taylor (2003, p. 1) calls "our death denying society", and Schnell, "the almost pathological American refusal to discuss the topic of death" (2000, p. 16). Although these commentators are discussing American attitudes, the descriptions can equally be applied to other Western societies (Blank, 1998; Finkbeiner, 1998; Gatenby, 1998; Grinyer, 2002; Ironside, 1996; Riches & Dawson, 2000; Rosof, 1994; Schiff, 1977; Staudacher, 1987; Talbot, 2002; Tonkin, 2006). Holcroft, a New Zealand writer, in discussing the New Zealand attitude to death, said that in a European-based culture, euphemism and platitude were used because the subject was considered unsuitable for conversation: "after a funeral it is usual in polite circles to talk of everyone or everything except the dead" (1989, p. 21). Ironside suggests this attitude developed after the two world wars, where, when death became so common, the kind of social acknowledgement practiced in an earlier era became impossible and led to the later clinical approach to grief (1996). Walter affirms this in his discussion of societal disapproval of the public expression of emotion, pointing out that in Anglo-American societies a stoic attitude in the bereaved is admired (1996).

Lewis wrote of the way people avoided him after the death of his wife, or felt awkward about saying something about his loss (1961, p. 7). This phenomenon seems to be even more pronounced after the death of a child. One of the reasons given for this behaviour is to avoid upsetting the parents by reminding them of their child (Gatenby, 1998). However, as Gatenby points out, parents never forget that their child is dead and the unwillingness of friends to talk about the dead child can result in parents severing those friendships. Schiff (1977) confirms that it is hard enough for parents to deal with their own grief without having to deal with the reactions of other people.

Schiff reports that bereaved parents find re-entering public life for the first time after the death a frightening experience. Because the parents' world has stopped, there is a feeling of shock to discover that, for other people, life carries on as usual. Returning to normal functioning in the first year after the death takes so much energy there is very little left to give to other people, yet, in Western societies, it is expected that the bereaved will resume normal functioning and return to work after a few weeks. If there is no outward sign of breaking down it is assumed they are "coping well" and "getting over it" (1977). However, as Schiff says, parental grief is a debilitating long-term experience that does not end after a socially determined interval.

## **THE LANGUAGE OF GRIEF**

To describe the status of a bereaved wife, husband or child, the words widow, widower and orphan are used. However, there are no words in the English language to similarly describe a bereaved parent. The vocabulary used in Western societies to talk about death is often euphemistic and clichéd, such as "passed away", "gone to Heaven", "laid to rest". Schiff suggests that a move to a less death-denying culture might begin with something as simple as changing this language and urges avoidance of such expressions, and using instead the unambiguous "death", "died" and "dead" (1977, p.7). The avoidance of direct language is also shown in typical condolence cards which show ethereal scenes and messages such as, "time will heal", "we are sorry for your loss", "your loved one is in a better place", while cards acknowledging the first or subsequent anniversaries of the death do not exist (Hedtkke, 2002). As Klass points out, clichéd condolences are easy to give, but extremely unhelpful to bereaved parents (1999). The following poem by Moran (1999) describes her frustration with such expressions.

*Please don't ask me if I'm over it yet,  
I'll never be over it.  
Please don't tell me she's in a better place.  
She's not with me.  
Please don't say at least she isn't suffering,  
I haven't come to terms with why she had to suffer at all.  
Please don't tell me you know how I feel,*



*Unless you have lost a child.  
Please don't ask me if I feel better.  
Bereavement isn't a condition that clears up.  
Please don't tell me at least you had her for so many years.  
What year would you choose for your child to die?  
Please don't tell me God never gives us more than we can bear.  
Please just tell me you are sorry.  
Please just say you remember my child, if you do.  
Please just let me talk about my child.  
Please mention my child's name.  
Please just let me cry.*

While using unequivocal language may better acknowledge the finality of death, the enormity of experiencing the death of one's child cannot adequately be conveyed within the limitations of spoken language. Grinyer's study (2002), based on the written narratives of parents of young adult children with cancer, identifies the difficulty parents have in finding words to speak of their experiences. This parallels the lack of vocabulary that Knapp's respondents revealed in describing their feelings on hearing the news of their child's sudden death (1986). Knapp makes the point that one reason for this is that parents' recalling such a traumatic event is "debilitating to their psychological stability" (p. 69) and is part of the defence mechanism of denial. The few parents who provided a written narrative were more explicit and said they found it easier to write than to talk about their feelings.

Written narratives by bereaved parents often rely on imagery to describe their grief: "...living in a world without colour" (Daher, 2003, p. 48). "...times of absolute blackness" (Edmond, 1991, p. 239). Images of waves and drowning are common: "...like a tidal wave, remembrance would come and engulf me and make me feel as if I were drowning" (Schiff, 1977, p. 25). "...waves of unimaginable misery" (Edmond, 1991, p. 239). Others write of cold and ice: "I feel as if I am walking across the Arctic snowcap... I know if I lie down I will freeze to death" (Schiff, 1977, p. 26). Rosof says: "A child's death is a dark stone dropped in the pool of your life. Ripples spread everywhere; no part of you is spared" (1994, p. 14).

One of the most harrowing elements in grieving the death of a child is the intense awareness of the empty space he/she used to inhabit. Schnell says: "...her absence [created] a vacuum that felt like it would suck the life out of us altogether" (2000, p. 13). Edwards, in writing of her son's death, puts it this way: "What we all had to face was not something present but something absent. And although one could escape something's presence there was, we discovered, no way to escape its absence" (2006, p. 116).

Marx and Davidson (2003) describe the feelings of parents who confront the moment when they no longer have a living child.

*If it were a picture there would be only darkness. If it were music, it would only be a cry of pain or for some, a single chord in a minor key – a chord extending beyond our ability to endure it. But the loss of a child is not a painting – it is not music. It is the colour of our pain. It is the desperate cry of our emptiness (p. 15).*

They refer to pain “so intense it blots out the sun” (p. 74). Finkbeiner describes it thus: “It’s as if the child’s life was a forward momentum that death interrupted, like a sudden stop in the middle of a song or dance... and the interruption is intolerable” (1998, p. 256).

## READING AND WRITING ABOUT GRIEF

Walter (2000) refers to the way all societies exert their cultural values on the public expression of grief as “policing”. In Western societies, the wearing of dark veils over the face at funerals of earlier times has been replaced today by large dark sunglasses to conceal the signs of grief. He suggests that the current proliferation of writing and public discussion by the bereaved is a rejection of society’s “policing” and “medicalisation” of grief. In addition, he claims, autobiographical books, magazine and newspaper articles, as well as radio and television programmes, in which well-known personalities describe their experiences of bereavement, have served to remove the taboos from what was traditionally considered private.

The link between the medicalisation of grief and writings by the bereaved is echoed by Frank (1995) who says: “The post-modern experience of illness begins when ill people recognise that more is involved in their experiences than the medical story can tell” (1995, p. 8). As noted by Arnold (2005), several studies (Bolton, 2000; Holly, 1989; Pennebaker, 2004; Robinson, 2000) have shown that writing about a traumatic event has a cathartic effect on the writer, whether the writing is private or intended for publication. However, another reason for writing about the deceased, is, Edwards claims, to prevent the dead “being erased” (2006, p. 116).

This fear of their children being erased from a society reluctant to remember them, may account for the rise in parents writing their own grief stories. Writing is also a way of continuing bonds (Klass et al. 1996; Walter, 1996). In addition, society’s embracing of a “confessional culture” has contributed to the growing genre of not only “life writing” but also “death writing” (Grinyer, 2006b; Walter, 2006).

While analytical studies contribute to scholarly understanding of grief, the clinical and academic language renders them largely inaccessible to bereaved parents. Schnell, an English Professor at the University of Vermont, says that after her infant daughter died, “words had turned on me. They were big, scary, medical terms... I was simply choking on words” (2000, p. 5). This difficulty with clinical language is reiterated by Duder, who says that after her daughter’s death she found nothing she could relate to in the academic literature on grieving: “What I could not easily find was some accumulated wisdom in the shape of written material, which truly cast light on my anguish, to show me how, learning from others further

on the same journey, I might deal with it" (Duder, 1998, foreword). Frank (1995) relates the story of a patient who was given books to read to help her understand her grief. She claimed the theoretical analyses of grief were of no help at all. The personal-experience stories, however, helped her recognise her own grief journey, not in the stages of traditional models, but in the kind of milestones that The Compassionate Friends refer to as "into their grief; well along in their grief; and grief resolved as much as it will be" (Klass, Silverman & Nickman, 1996).

Reading about the experiences of others provides a guide in an unfamiliar landscape, though, as Frank points out, people tell stories "not to provide a map that can guide others – each must create his own – but rather to witness the experience of reconstructing one's own map" (1995, p. 17). Schnell (2000) says that when her daughter died she read books on grief "as if my life depended on it..." (p. 15). She was persuaded to go back to work as an English Professor when a colleague reminded her that one of the primary relationships in her life was with language, and the redemptive power of language might be her way back to healing: "I might stop choking on my words" (p. 7). She discusses the Book of Job as her inspiration to write her story. "If I had lost my ability to tell my own story, Job reminded me that it was important to at least keep on trying, that there might be the possibility of a new narrative – that I might, metaphorically, get my stuff back – if I learned how to tell" (2000).

Writing poetry was the way Edmond "got her stuff back". She launched her first book, *Middle Air*, in 1975, a year after her daughter's death. In her autobiography, she wrote: "this new work, my own writing, was the beginning of my next journey" (1991, p. 241). Two years after her daughter's death she became aware of "... a need to widen and strengthen the whole shape of my consciousness to accommodate the fact of her loss and to learn the ways in which I could keep my knowledge of her fresh and untarnished by bitterness" (1992, p. 45).

Allende found catharsis in writing her daughter's story while attending her daughter, who lay in a coma for a year before she died. At the end of her book, she wrote: "I am Paula and I am also Isabel. I am nothing and all things in this life and others' lives, immortal. Godspeed Paula woman. Welcome Paula spirit" (1995, p. 330).

## A CREATIVE NONFICTION PERSPECTIVE

The lived experience of bereaved parents in written narrative not only informs the data gathered in clinical studies (Grinyer, 2006b), and facilitates catharsis in the writer, (Bolton, 2000; Holly, 1989; Pennebaker, 2004; Robinson, 2000) but also contributes to what Duder refers to as "accumulated wisdom" to guide others at the beginning of their grief journey (Duder, 1998, p. 7).

Creative nonfiction is a genre that lends itself very effectively to describing the grief journey from inside the skin of a bereaved parent. "Floating in the margins between fact and fiction" (Cunnane, 2007, p. 10), creative nonfiction has the advantage of being able to cross genres to weave factual reporting with

the techniques of fiction, poetry, lyric and personal essay, memoir and critical analysis into a more compelling narrative than reportage or fiction can do alone (Forché & Gerard, 2001; Gutkind, 1997; Roorbach, 2001). This genre is, as Forché and Gerard assert, "expansive enough to connect the self to the larger world of experience, shaping its form, to tell the truth of a particular moment" (2001). Sometimes referred to as the fourth genre, literary nonfiction, factual fiction, documentary narrative, and literature of actuality, creative nonfiction differs from fiction in that it is fact-based, and from nonfiction in that the full range of literary devices of the fiction writer may be used.

Gutkind argues that the more a piece of writing rings true the more it touches readers. The difference between believable fiction and believable nonfiction is that while it is essential for fiction to *ring* true, nonfiction has to *be* true (Gutkind, 1997). Unlike the objective reporting of non-literary nonfiction, in creative nonfiction the subjective is not only allowed, but encouraged, enabling readers to live the experience (Gutkind, 1997; Roorbach, 2001; Steinberg & Root, 1999). This connection is what Frank (1995) refers to as writer and reader "entering the space of the story for the other" (p. 18) and parallels Schnell's experience with the books on loss that she read to help put her own grief into perspective. She says her identification with the writing "became part of what felt like the cellular structure of my grief" (2000, p. 15). Her appreciation of the works "went beyond simple identification, to a literary critical appreciation of the way language was working in these powerful pieces of writing" (p. 15).

Addison, an Australian writer, tells the story of the death of her nineteen year old son Charlie, from cancer, in *Mother Lode: Stories of home life and home death*. The book begins, "Let me tell you my stories. I'm ready now. I've steadied my voice" (p. 1). Addison describes the grief of her family through the months of caring for Charlie, until his death. There are stories of Charlie's life while growing up, the diagnosis of his brain tumour and dealings with health professionals, and the stories his mother "swaddled him in" while he was dying, just as she did when he was a child. There are also stories about the deaths of Charlie's grandparents and the comparison of death at the end of a long productive life with one that occurs when adult life has hardly begun (2001). A reviewer, Bond (2006), says, "For those who have experienced the death of a loved one, particularly a parent or a child, this book of stories will sometimes be a gentle salve."

In conclusion, clinical models of grief have been developing over the last two decades, from an assumption that recovery depended on successful detachment from the deceased, to the recognition of the importance of continuing bonds, particularly in relation to parental grief. On-going scholarly debate on the grieving process is necessary to build on existing knowledge, especially in the area of grieving the death of a young adult child from cancer, where current research is sparse (Cacace & Williamson, 1996). Health professionals and communities who help support the bereaved in the long process of relocating themselves benefit from new insights into the grieving process. However, as studies of bereaved

parents have shown (Dean et al., 2005; Grinyer, 2003; Riches & Dawson, 2000), those supporters who have not undergone the emotional trauma of burying their own child can never fully empathise with the experience of those who have.

Riches and Dawson (2000) point out there is power in story telling, which may be used as a tool to help the bereaved construct a new reality. As Morgan (1985) says: "We may not know what we think or feel until we have heard ourselves saying it" (as cited in Riches & Dawson, 2000, p. 186). Such a narrative may also provide other bereaved parents with an accessible resource and add another dimension to the current body of academic knowledge, by illuminating theory with lived experience. As Grealy (1996) says: "Sometimes the closest we get to answering the saddest questions life asks us, is to respond in the most beautiful language we can muster".

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