1 Introduction

Chapter contents

- Basic definitions
- The importance of the social worker as the reflective practitioner
- Examples from contemporary dramas: novels, film and television, biographical accounts
- Scenarios that will be drawn upon throughout the text
- The major ways of assessing loss, including issues of difference and anti-discriminatory/anti- oppressive practice
- Core theme of 'living psychologically beyond our means'
- The structure of this book

This chapter introduces the reader to this text, setting out how it is organised and its contents. It starts out with some key definitions, an overview of basic concepts including understanding and assessing the experience of loss, incorporating the impact of gender and race/ethnicity and from this point exploring the meaning of anti-discriminatory and anti-oppressive practice. Underlying all this is the text's core aim: how we can be helped to recognize, rescue and revive the social work role within our work with loss, death and bereavement.

In focusing on social workers this is not to deny that there are, of course, a host of other professionals and lay people with important parts to play. Health care workers, teachers, bereavement counsellors, those involved in pastoral responsibilities: all take on the caring/curing role, working alongside social workers in the wider community and multidisciplinary teams. Hopefully this text will be useful to all or any of these groups but there is already a body of writing intended for this audience. This is less so for *social workers*, those individuals whose precise roles may change across agencies, different service user groups and countries, whose titles might shift and slide between *social care worker*, *mental health worker* or *care manager*, but who share a body of theories, skills, values and roles which are broadly similar.

Concentrating on what may be called *mainstream social work* means paying attention to the needs of service users when someone important to them has died, or they face losses related to disability, life limiting conditions, the onslaught of mental ill-health, ageing and the disasters that befall family life and child care. The discussion will draw on, but not seek to compete with, the more specialist texts that are already available on palliative care (Berzoff and Silverman, 2004, Firth et al., 2005, Beresford et al., 2006,) or the experience of those who are dying (Armstrong-Coster, 2004).

Integrated into the text are various case scenarios linking the experience of both service users and workers with the theories, research studies, professional values and practical skills that we can draw upon. Examples will also be taken from films, novels and personal accounts while self-tests, point for practice and advice on further reading help readers to stay in touch with your own processes, check and advance your knowledge and indicate where else you might go to consolidate and broaden your understandings. Readers are always encouraged to return to the various texts and authors that are cited, to check your own understandings and develop your own criticisms rather than relying on what other people, including this writer, have said they said.

To start with, however, what follows are some general working definitions.

Some Working Definitions

Loss   is wider than a response to a death, important as that is. It is any separation from someone or something whose significance is such that it impacts on our physical or emotional well-being, role and status. The experience and manifestation of loss can be more or less difficult depending on other important variables. This is explored in fuller detail in Chapter 2.

Dying   Bob Dylan expressed it well when he sung: 'he not busy being born is busy dying' (1965). Professional definitions tend to be more prosaic: '*Medical practitioners* usually draw distinctions between *chronic illness/disabilities* which are *life limiting* and *diagnosed terminal conditions* such as cancer or motor neurone disease, needing *palliative care. Sociologists* discuss the various degrees of *aware dying* ranging from *closed* through to *open* awareness' (Glaser and Strauss, 1965: 10) (emphasis added).

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Writing as a *social worker*, Currer sees dying as involving '1) a degree of physical deterioration, 2) an emotional or individual component concerning the self (possibly incorporating a spiritual dimension) and 3) a social dimension about interaction with others' (2001: 38).

Death, outside of strictly medical terminology can prove difficult. Broadly speaking there is: *Living death* or a s*ocial death* e.g. lying in a coma, suffering from dementia, imprisonment. Individuals are physically alive but their situation isolates them from their former familial or social links.

Psychosocial death (Doka and Aber, 2002) where someone's *psychological essence* or *sense of self* is perceived as having died. This may be through drug dependency, mental illness, coming out as gay, joining a cult, undergoing a religious conversion or, the opposite, losing one's belief, e.g. some orthodox Jewish parents will formally mourn, sit *shiva*, for a child who marries out of the religion and the community.

Bereavement is the response to a loss. It is a core human experience, common to, and also varying across, all cultures and historical periods. *Grief* is the *intrapersonal* or *psychological* expression of the bereavement. *Mourning* is the *interpersonal* or *social* expression, taking its clues from the attitudes and values of the surrounding context, religious, cultural etc. Both the intra and inter dimensions serve to sanction, or disallow and disenfranchise peoples' reactions. Within these general definitions there are those specific to the role of the social worker.

There is discussion about the word we use for those who turn to social workers for support, whether the traditional term, *client,* or even *patient* in some specific work settings or more recent phrases like *service user.* The latter is the most popular currently so it is this I will use in the text, except, of course, where citing other sources.

Once engaged with service users Currer draws attention to the need to combine in our work 'the Emotional and the Practical' (2001: 78); Berzoff and Silverman refer to the need to draw on 'the physical, psychological, social, spiritual and existential' (2004: 8); Farber et al. comment on how

social workers need to be 'consultants, collaborators and guides' to those private individuals newly caught up in the uncertainties of significant loss (2004: 115).

This text highlights the importance of the social worker as *a critical and reflective practitioner.* There are many definitions of this concept, certainly it incorporates the skills, theories, values and evidence base of our work and this text seeks to integrate, implicitly and explicitly, these aspects throughout. It also incorporates the all important elements of action and analysis and the need for practice to develop through a commitment to questionning of what we do and why rather than being defensive. Adams uses the phrases 'engaging with ourselves', 'engaging with knowledge', 'engaging with practice' and 'engaging with paradoxes and dilemmas in developing our own critical practice' to represent the various processes (2002). Fook suggests the phrase *critical reflection* to embed within practice:

> the intuition and artistry involved in professional practice … the importance of context and interpretation in influencing action … each person engages in a process of theory-building by reflecting on their own practice. What is also to a critical approach – which is not necessarily articulated in a reflective stance – is the *emancipatory* project, the capacity to analyse social situations and to transform social relations on the basis of this analysis (emphasis in the original) (1999: 201–2).

Telling Tales: Dramatic Tales of Loss, Death and Bereavement

The above discussions illustrate how our understandings of loss, death and bereavement cannot be captured in a neat turn of phrase. Perhaps we can be brought nearer to its essence by stepping back from the strictly professional arena and looking to literature and other cultural forms. Dinnage (1992) draws on poets such as Coleridge, Browning and Owen, Silverman (2004) turns to the classic images of Antigone by Sophocles and Michelangelo's Peit? while for many music is the compelling medium; funerals, cremations or memorials accompanied by hymns, selections from the great composers or more contemporary choices, such as 'I Did It My Way' and 'Knocking on Heaven's Door'. In Canada a university focuses entirely on novels and autobiographies by way of introducing palliative care to health students (Hall et al., 2006).

This medium has its limitations, of course. Freud notes the attraction of fiction and theatre as a way of fulfilling our need to 'find people who still know how to die … . We satisfy our wish that life itself should be preserved as a serious stake in life'. Further, fiction offers us all a 'second chance … We die with the hero: yet we survive him, and possibly

die again, just as safely, with a second hero on another occasion' (Freud, 1915/1993). Modern commentators are also cautious. Gibson (2001) believes that cinematic death bed scenes can emotionally distance audiences while Davies comments that, for all our familiarity with death on the television and cinema screen, this 'is largely devoid of serious impact' (2005: 16) since it does not relate to intimate deaths of people close to us.

Nonetheless, such dramatic stories do serve an important role. Bettelheim, in his classic study of fairy stories, argues that they help the child 'make some coherent sense out of the turmoil of his feelings. He needs ideas on how to bring his inner house into order' (1991: 5). The following examples suggest that the stories, or narratives as they are increasingly termed, expressed in contemporary film, television and novels help bring order to the inner house of today's adults.

Scenes From Contemporary Dramas

Interestingly many successful British films use death as a powerful counterpoint to humour. *Four Weddings and A Funeral* (Newell, 1994) sets the funeral scene against the celebrations and portrays the depth and range of passion and pain which is felt by the various mourners: parents, friends, gay lover. *Love Actually* (Curtis, 2003) starts with scenes set in an airport, people hugging their greetings, as a contrast to all those who never arrived because on 9/11 their planes crashed into the twin towers, the lesson of their deaths is to love more. In *Calendar Girls* (Cole, 2003) a group of middle aged women pose nude as a charity stunt. Since this is also a memorial to a husband it shows, amid the humour, something of the obsessions of mourning and the disruption it can cause within friendship groups.

Death is a metaphor in more seriously intended, iconic, films such as *Field of Dreams* (Robinson, 1989) where legendary, and long dead, baseball players gather for one last game and assert the survival of American values as well as providing the opportunity for personal and political healing. Death comes as a climax in *One Flew Over the Cuckoo's Nest'* (Foreman, 1975) when Chief Bromden kills the rebel hero McMurphy, who the mental hospital professionals have already mentally murdered by means of a lobotomy. Loss is represented not just in this death, it is there in the loss of liberty, either enforced since McMurphy is detained under an order, or surrendered, since most of the fellow patients are there in a voluntary capacity. Chief Bromden, a native American, is an elective mute, becoming voiceless when, despite the verbal protests of the elders, the tribe is forcibly moved to a reservation. Loss is played out on many levels in this story, as is the redemption in Bromden's escape to freedom.

A more prosaic style is chosen for the film *Last Orders* (Schepisi, 2002), based on the award winning Swift novel, (1996) which follows the misadventures of a group of South London working-class men struggling with their own clumsy feelings about grief while following their dead friend's last request to have his ashes scattered into the sea. Mourning is portrayed in *Truly, Madly, Deeply* (Minghella, 1991), where the partner of a young woman, Nina, dies suddenly. This is, in some ways, a very realistic presentation of the pain of her loss, deeply felt in her counselling sessions and repressed in the face of the sheer ineptitude of family and friends who want to help but have no idea about how to reach her. The non-straightforward aspect lies in the way that Nina moves from the 'normal' sensing of the lover's continued presence around the home to his becoming a very real manifestation. They play, bicker and make love, much as they had before his death, until Nina escapes the thrall of this all too fleshy ghost and is ready to move on with another relationship.

This theme is played out more fully in television series. As I write the weekly schedules include repeats of *Six Feet Under* (Ball, 2001-2005), about a family business of undertakers, and two programmes featuring reluctant mediums, *Ghost Whisperers* (Fox, 2006) and *Afterlife* (Volk, 2005–2006) whose strap line is: 'You don't contact them, they contact you'. Similarly in the best selling novel *The Lovely Bones* (Sebold, 2002) the dead are as real as the living characters. Throughout these stories the dead are continually interfering, not always benevolently, in earthly events, offering wry comments and advice, like more modern and so acceptable versions of those voices that mediums provide at séances. Staying with séances, the novel *Beyond Black* (Mantel, 2005) is an always engaging story of a modern day sensitive.

Another important dimension is the impact of loss on those who are professionally involved. *Bringing Out The Dead* (Scorsese, 1999) is stark in the detail of a weekend night duty of a New York paramedic, Frank. The shift is fuelled by pizzas, blood, adrenaline and the urgent calls from the ambulance radio summoning him to the next crisis. Frank wants to save lives, in those moments it is as if 'God has passed through you ... God was you' but most of his time is as 'a grief mop', witnessing peoples' deaths, seeing 'the spirits leaving the body and not wanting to go back'. He comments that there are a lot of 'spirits angry at the awkward places death has left them'. One such spirit is Rosa, a young woman who collapsed and died on the sidewalk and who Frank now sees again on the faces of passing strangers, the homeless and the prostitutes. Rosa's face is reproachful, sometimes words go with the accusing stare and he hears her demand 'why did you kill me?' Frank finds no way to answer her.

The main character in the film *The Son's Room* (Moretti, 2001) is a psychotherapist and the film follows the impact upon him, personally

and professionally, of the accidental death of his son. Apart from the seismic shifts within his family he is also put in a very different place with his clients as he contrasts his own trauma with what now appears to him as the lesser complaints of 'the walking wounded'. The film ends with him apparently abandoning his practice, the loss of his son entailing also the loss of his profession.

This discussion cannot ignore those books which are personal memoirs, or confessionals, which have proved immensely popular. A few examples include the accounts by Diamond (1998) and Picardie (1998), both dying from cancer, reflections by an orphaned son (Morrison, 1998) and a widowed wife (Didion, 2006), and Bayley (1999) and Grant (1998) on living with dementia in the family. These are difficult books, condemned by some as part of 'the sentimentalisaton of modern society' (Anderson and Mullen, 1998) and it does seem that many need these accounts, all by already established writers, to reflect back and give words to their own experiences.

Exercise 1.1

Impact of television, names or television on you?

1. Reflecting on a film, novel or television drama is there a particular scene that has stayed with you and helped you think differently about loss, death and bereavement?
2. How and why has this moved you?
3. Has the dramatic impact of death meant that less consideration is paid to other forms of loss?
4. These mainstream films and books reflect a variety of experiences but all are rooted within the white population. Can you think of more ethnically diverse examples and how different might these stories be?

The scenarios

The stories above serve as an introduction to the discussion, those below are a bridge into the rest of the text for our central concern must be the experience of service users, represented through the scenarios, which are expanded upon in the subsequent chapters. There will be two major scenarios in each chapter, one relating specifically to death-related loss and one to loss in its wider context.

All the scenarios are based on real situations known to me personally or professionally or shared with me by colleagues but all identifying details have been changed to ensure confidentiality:

1. *Kuldip,* or Kay to her work colleagues, came to the UK from Pakistan as a child. Her mother was dead, her father a political exile. Now 38 and single, she looks after her sick father while also holding down a demanding job in publishing. She is Muslim, in cultural rather than religious terms, an identity she felt happy with until she felt the tensions around her grow after 9/11 and 7/7. Eight months ago she collapsed at work and despite many subsequent tests and examinations there is no clear diagnosis, just a viral infection, cause unknown.

2. *Marcia* is 17, is a bright young girl from a family not previously known to social services although there have been increasing concerns from school about her deteriorating standard of work. Marcia is now due to appear in court following her involvement, with a group of girls, in a series of violent, drink fuelled incidents. A year previously her father had died of throat cancer and she had been a primary carer. Her mother is a nurse and she has a younger brother.

3. *Mat*, 34, is in the terminal stages of an AIDS-related illness and *Douglas*, an ex-lover, moved back to be the primary carer. When Mat's mother, *Mary*, comes to the city where the couple live she insists that is her role to look after her only son. Not previously knowing about Mat's sexuality she now refuses to accept that he is 'really' gay or that he is dying. Douglas, and other gay friends, are banned from the house and denied any role in planning the funeral.

4. *Lou*, 77, had been married to *George* for 59 years. He suffered from Alzheimer's Disease for ten years and Lou had been nursing him at home up to a few months ago when their children eventually persuaded her that he ought to go into hospital for an assessment. He died there very quickly. Lou now lives alone, is in ill health and isolated. Although her four children are in the area they are preoccupied with their own families.

5. *Susan* is 37, pregnant by her husband *Daniel* and with two daughters, *Denise,* aged 10 and, *Sarah,* 8, from an earlier relationship. Despite the pregnancy being difficult Susan has taken as much care of herself as she can manage. In hospital, however, the baby has to be delivered by a Caesarean operation and when Susan wakes up from the anaesthetic, in a side room on the maternity ward, she learns that her baby, a son, died shortly after birth.

6. *Lorraine* and *Michae*l are in their early forties with an only child, *Wanda,* aged 12 who has Cystic Fibrosis. They try to be very positive

about Wanda, love her deeply but are becoming increasingly concerned as she becomes an adolescent and suddenly begins to resist the treatment vital for her continuing health. They wonder what life will hold for her and feel sad at what they fear she, and they, will miss out on.

7. *Dorothy* is 45, married with two sons in late adolescence and a husband, *Max*. They have just celebrated their 25th wedding anniversary. If asked to comment Dorothy describes herself as 'contented and conventional', 'at peace with myself after a difficult adolescence'. Quite unexpectedly she has heard from an agency that a son that she had when 15, who was then adopted, is now wanting to meet her.

8. *Peter* is 55, black British, living alone in the inner city. He is unemployed, apart from occasional cash in hand casual work. In his late adolescence, shortly after the sudden death of his father, he had a breakdown and was sectioned but has not been hospitalized for the last ten years. He feels his life has been wasted and his only comfort lies in his music and his sense of being a spiritual person.

9. *Sam* is 72, working class, described by neighbours as previously 'a well turned out, quite dapper gentleman' until six months ago when his wife, *Mavis*, died of lung cancer in the local hospice. He has children but they live out of the area. Sam is now wandering the streets, looks quite dishevelled and seems distressed but is unwilling to talk to anyone who approaches him.

Exercise 1.2

Your reactions to the scenarias

- Select the scenario that most impacts on you.
- Reflect on the impact of the losses on the individual(s) involved.
- Reflect on your own emotional and cognitive responses, first on a personal level, then as someone who could, potentially, be called upon to help professionally.

Understand]ing and Assessing Loss

Because these scenarios are so varied, although loss is a central motif, what emerges is a need for further clarity about how the phenomenon can be assessed. Practitioners and researchers have reached for some understanding and some of the key themes are outlined below.

Major Ways of Assessing Loss

- The nature of the attachment
- Sudden or anticipated death
- Traumatic bereavement
- Personality of the bereaved
- Life complicated by a crisis other than the bereavement
- Social factors
- Age
- Religious belief
- Unsupportive families
- Unsupportive communities
- Issues of diversity, disadvantage and discrimination such as race and gender

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The nature of the attachment: as will be explored in Chapter 2, Bowlby (1991) reminds us how much flows from the part the deceased, or the other forms of loss, whether of employment, intimate relationship or country, played in the emotional well-being of the survivor.

Sudden or anticipated loss: anticipation can reduce the trauma of loss or bereavement (Parkes, 1980) while being unprepared can be 'a predicator of risk of psychological or physical disability' (Stroebe and Stroebe, 1987: 239). A loss needs to be integrated into an already *existing worldview*, allowing either a fatalistic acceptance or the need to 'gradually reformulate their (the bereaved) view of the world to incorporate the event' (Wortman and Silver, 1989:364).

Traumatic bereavement: a traumatic dying can cause angry and self-reproachful behaviour (Parkes, 1975, Raphael, 1977) while distress can be caused if religious funerary rituals, e.g. involving preparing the body, are ignored (Eisenbruch, 1984).

Personality of the bereaved: a grief reaction can highlight other problems in the individual's personality, reawakening feelings of *learned helplessness* (Seligman, 1992), previous patterns of relationships (Pincus, 1978) and losses (Bowlby, 1991, Marris, 1996), reactivating mental illness or addictions to alcohol or drugs (Worden, 1991).

Life complicated by crisis other than the bereavement: various writers (Worden, 1992, Parkes, 1998) indicate clearly the degree to which loss may require difficult and sudden changes in life style, such as loss of income or moving home. This features often in the research of widows (Raphael, 1977, Van den Hoonaard, 2001).

Social factors: class allegiances, membership of religious groups or ethnic communities can provide guidelines and rituals to follow. Losses can seriously affect material circumstances, causing homelessness, poverty or other economic difficulties.

Age: the *young* bereaved often experience greatly increased physical distress and drug use for symptom relief (Parkes, 1975, Stroebe and Stroebe, 1987). Wortman and Silver (1989) suggests that the initial impact on younger spouses is greater but they recover more quickly than older widows/widowers. *Older people* are often assumed, because of their age, to have grown used to losses and deaths and are psychologically 'disengaging' from life. But these ageist attitudes 'mask the grief symptoms from the eyes of onlookers' (Barker, 1983: 15) and the ability to grieve 'may be lessened because of many losses in an abbreviated time period' (Worden, 1991: 128).

Religious belief: Stroebe and Stroebe sees no evidence of religious belief helping individuals cope any better with their loss (1987: 218) but one third of the widows in Van den Hoonaard's study found that religion was very important, providing the comforts of both a personal faith in God and a 'powerful connection to the community and a church family' (2001: 123).

Unsupportive families: widows were clearly adversely effected when families were physically and/or psychologically unavailable (Parkes, 1975, Raphael, 1977) and mourners were restrained from expressing their feelings, especially negative ones (Barker, 1983).

Unsupportive communities: Young and Cullen refer to the need for the bereaved individual to draw on 'communal existence' (1996: 161), where the story of the death can be heard and 'human solidarity' offered (1996: 183). This reinforces the idea of grief as a 'social process' with the need of the community to come together to construct 'an enduring and shared memory of the dead' (Walter, 1996: 14).

Difference and Discrimination: the need for Anti-discriminatory/ Anti-oppressive Practice

One of the distinctive qualities of contemporary social work is its open recognition of the divisions in society and the way that these impact on the way, firstly, that individuals become service users and, secondly, how we as professionals need to respond. There are quite profound problems, however, in how we phrase this understanding, whether we prefer the phrases 'ethnic sensitivity' and 'cultural competence' over 'anti-discriminatory practice' and then again whether this is synonymous

with 'anti-oppressive practice'. There are sharp debates as to whether the major signifiers in a service user's experience come down to their gender or their ethnicity or their class or their age: questions that can face us with what has been called 'a hierarchy of oppressions'. The scenarios above will have touched on how these concerns can be felt when we work with loss, death and bereavement, the subsequent chapters will allow for a fuller exploration while the paragraphs below serve as a short introduction to the major themes.

Bereavement and Gender

Gender is an obvious issue when reflecting on loss, and immediately illustrates the difficulty in finding common ground. For the feminist writer, Cline, raising the subject of 'women, death and dying' 'breaks through our most sacred taboo' so hidden is the 'specific relationship women have to the dying process' (1995: 1). Walter makes an opposite point; it is not women's experiences which are peripheral but men's since most theories of grief are based on researching women, especially widows (1996: 21).

What does seem uncontroversial is that men and women tend to grieve differently. Riches researches bereaved parents, noticing the 'gendered patterning' of grieving (2002: 80) with women attending to the 'emotional labour' of grieving while men intellectualise their loss or take on practical tasks, trying to maintain continuity in their life, as the wage earner, or involved in loss related activities such as fund raising for cancer charities. Men/fathers who admit grieving express their emotions in private with support groups, counselling sessions or visits to clairvoyants left to their female partners (2002: 85).

Cline reminds us of the cultural context for this: how, historically, tending for the dead and dying has been 'a communal and female event (undertaken by) traditional female specialists' (1995: 44) and that a socially constructed emphasis on women's caring and expressive roles is further reinforced by biology, the potential of pregnancy involving simultaneously a life growing in the womb and 'the spectre of death' which 'may be the core of women's perception of death from "inside"' (1995: 24). In today's society it may be that women have retained the caring role but without any of that community support, thus Young and Cullen's (1996) warning that where a patient is terminally ill the demands on the main carer, usually women, are considerable in terms of increased isolation and dependence on, and preoccupation with, the dying person.

Drawing on extensive research, Stroebe and Schut (1999) conclude that widowers are relatively worse off than widows, with higher rates of depression and other health consequences, including mortality rates.

Men's past dependency on their wives can then leave them socially and emotionally isolated. Research further suggests that men are more likely to see bereavement as a problem to be resolved by drawing on their own resources and thus 'turning ..., to distracting activities' (Stroebe and Schut 1999: 86). This provides immediate relief but men are more likely to become depressed subsequently. Women are more immediately expressive, confronting their feelings, seeking out support but neglecting the other practical needs which also need addressing. Stroebe and Schut conclude that what is needed is 'a healthy mix of both male and female ways of coping, a confrontation and avoidance of both emotions and problems, an oscillation in attention to these dimensions' (1999: 86). Many social workers have come to see this *dual process model* as an enormously helpful way of working with the bereaved.

Bereavement and Race/Ethnicity

While gender is a widely acknowledged and debated aspect of loss, death and bereavement there is far less material on race and ethnicity.

Stroebe and Stroebe, reviewing the research on health and risk factors in bereavement, are unable to reach any meaningful conclusions concerning ethnic differences given 'the limited evidence and the problems of interpretation' (1987: 191). This is a revealing comment and certainly race and ethnicity are more usually considered in terms of anthropological studies of distinct and often distant societies (Stroebe and Stroebe, 1987, Robben, 2004) or descriptions of different religious practices (Nueberger, 2004).

It is important that social workers remain alert to this gap in the knowledge and draw on what is known. Kalish and Reynolds suggest that 'Anglos' are more 'death-avoidant' and less in contact with the dying and with death than other ethnic groups (1981: 27). It does seem that minority communities are more likely to retain religious beliefs and cultural patterns that support the mourning process, the Irish wake, the Jewish shiva, the rituals in Islam and Hinduism, but acculturation and assimilation means that when influenced by the majority culture these customs fade. The novel *Disobedience* (Alderman, 2006) gives a poignant picture of the supportive process of mourning within an orthodox Jewish community and the disruptions caused to this by the return of the deceased rabbi's 'heathen' daughter. Grieving considered to be excessive by Eurocentric standards can also lead to inappropriate diagnosis by mental health professionals (Littlewood and Lipsedge,1997) and Eisenbruch (1984) suggests the following questions that can increase professional understanding.

Ethnic and Cross Cultural Variations in the Development of Bereavement Practices (Based on Eisenbruch, 1984)

1. What is the individual's perception of the best way to die?
2. How does the individual perceive different types of death, for example, that of a child or a suicide?
3. What are the procedures involving the body of the deceased and any other burial rites?
4. Who are the principal mourners and how are they expected to behave, what is expected or prohibited in the days, weeks or months of the specified period of mourning or at anniversaries?
5. How might these practices be influenced or diluted by the expectations of the Western host society?
6. How is the dead person perceived in terms of their spirit, possessions?

Such aides can help social workers become more culturally competent, the term that is becoming increasingly common within health and social care. This is important for as Raiff and Shore remind us when writing on community care:

> Minority group members are latecomers to many different systems of care. They are less served by preventative services, more often routed to punitive, custodial settings and are more frequently ignored. They are … invisible. (1993: 66)

And 'culture' does not just relate to different ethnic groupings. Returning to the scenarios it may be that 17-year-old Marcia whose father had died, Wanda who has Cystic Fibrosis and is on the edge of adolescence or the two young daughters of Susan, Denise and Sarah, just 10 and 8, whose half-brother is stillborn, may, for all their obvious differences, share a common experience of being young people confronting unanticipated losses with feelings that society is uncomfortable allowing them to express. Ageism may be apparent also at the opposite end of the spectrum in the experience of 77-year-old Lou.

There is a further layer when disability activists defy discussion that sees their situation as a deficit model compared to 'normal' people and so they make claim to a community that is based on a shared culture. Readers will be returned to these themes when we meet Kuldip,

suddenly struck down by a virus, Mat and Douglas, caught up in the AIDS crisis and Peter, living with what has been termed an enduring mental health problem.

In all of these arenas it is important that the social worker is able to enter the world of the individuals concerned, to see what differences belong with the wider cultural expectations and the strengths this may bring in the face of adversity. This is the gift of *cultural competency*, 'a dynamic process of framing assumptions, knowledge and meanings from a culture different from our own' (Bartol and Richardson, 1998: 23) and we can never be complacent. As Gilroy reminds us, talking of the black communities but with, I suggest, wider implications: cultures are 'never fixed, finished or final. It is fluid, it is actively and continually made and re-made' (1992: 57). Desai and Bevan (2002) remind us also of the need for a wider perspective, one that recognizes how insidious and persistent racism eats away at an individual's sense of self esteem and identity, leading to a cumulative sense of loss, alienation and exile. Holland (1992) suggests that 'loss' is too small a word in these circumstances, it is 'expropriation'.

This brings us then from working with 'difference', a relatively neutral term, to an appreciation of the wider dimension of discrimination and oppression, from understanding the diversity of people and groups to 'a focus on combating institutionalised discrimination in society, which represents the interests of powerful groups' (Payne, 2005: 269). Payne provides a full and careful history of what these terms mean in the context of social work and we are fortunate that we have theories and models that can integrate what may otherwise seem confusing or contradictory. Especially helpful is Thompson's PCS (Personal Cultural, Struchural model first presented in 2001 for a general social work audience and its applicability argued for loss in 2002.

Thompson's PCS Model (2001, 2002)

P stands for *personal* and it can be extended to *practice* and also to *psychological.* It focuses on the individual: feelings, attitudes and actions.

C is for *cultural,* those 'shared assumptions and meanings … the framework of values, beliefs, codes and so on that become part of our individual and group identity' (2002: 10) so it further includes *community*.

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S represents *structural,* the impact of society and the power relations embodied in the social divisions that include race, gender and class.

These are not either/or considerations but must be interrelated and offer a holistic overview.

Various contributors to the Thompson text (2002) specifically flesh out this model to help underpin their discussions of gender and race. I certainly encourage readers to return to Thompson and see how useful his ideas are in both their clarity and comprehensiveness. In this text I use the model implicitly rather than explicitly as the discussion moves through the psychological theories, mainly as it connects to the individual (Chapters 2 and 5) and then to wider social and cultural/collective considerations (Chapters 3 and 6).

I take up two main threads throughout this text to inform my understanding of *anti-discriminatory practice*. One of these is *disenfranchised grief*, recognizing and valuing those forms of losses that are often disregarded within the wider society. The other is *narrative* which builds on the conventional strengths of social work, namely to hear the story that the service user brings, but develops this to make it a more active process where the individual is helped to see that they do not just have a voice but that it is as equally, or even more, important than that of the professionals whose views are normally given more prominence. It seeks to help the individual become the subject, not the object of their story. At times this perspective allows the individual to become part of a collective outside of their immediate family and community and to actually campaign and change aspects of their experience. The scenarios offer glimpses of this, whether it is challenging social workers removing children from their racial communities, on forcing medical systems to value and fully mourn stillbirths and developing forums where older people and service users can become involved in local and national advocacy groups. It is in these latter examples that I see the potential for *anti-oppressive work* and recognise that this normally arises from outside the profession rather than as a result of our own initiatives.

A Core Theme: 'Living Psychologically Beyond our Means'

The discussions above touch on a range of issues and, for all their brevity, do serve to indicate the many ways that 'grief … adds a new

dimension to a person's life' (Davies, 2005: 16). Indeed, the feelings can be of such power that Freud suggests that:

> In our civilized attitude to death we are living psychologically beyond our means … Would it not be better to give death the place in reality and in our thoughts that is its due and to give more prominence to the unconscious attitude towards death that we have hitherto so carefully suppressed? (1915/1993: 38)

By 'civilized' I understand Freud to mean all the ways that he saw people denying or sublimating the reality of death and, since he was speaking in the shadows of the killing fields of the First World War, he was probably reflecting on the gap between the images of brave soldiers going off to war and fighting heroically and the reality of boys dying horribly in the trenches or stretched out in no mans land. While such war torn contrasts are still with us, other 'suppressions' are revealed in our habitual ways of thinking and behaving. Whatever our feelings about the deceased we automatically refer to them as 'a loved one' and adhere to the old adage 'don't speak ill of the dead'. Many still say 'the c word' rather than 'cancer' and find euphemisms for AIDS while memorial notices describe people 'passing away' or 'gone to sleep' or dying after a 'brave fight'.

There are good reasons, of course, for this reluctance to look death in the eye. Latner talks of 'the terrible despair of mourning': we risk being close to another human then their death suddenly brings us into 'contact with emptiness. We look into the abyss' (1986: 67). We are also reminded of our own mortality which is a terrible puzzle for, as Becker reminds us, we each have 'a mind that soars out to speculate about atoms and infinity… At the same time man is a worm and food of worms. This is the paradox: he is out of nature and hopelessly in it' (1973: 26).

Even when we think we have reached some sort of peace with death and dying this can be revealed as most precarious. Deborah Hutton interviewed by a *Guardian* correspondent about her book (2005) offered advice on how people with terminal cancer, like herself, can be supported by friends and relatives:

> Halfway through … Her husband interrupts to tell us that people are feared dead following bomb blasts. It means that her book launch … that evening will be cancelled … She doesn't react immediately, but later tells me that she savours life more than before her illness … I feel that each moment is exquisitely precious. I love the rain, I love the clouds, I love the sun. Each day feels like a gift, and of course it is. And now out of the blue, all those people who expected to have infinite time won't be going home this evening (the *Guardian*: (Jeffries, 2005) 12 July 2005)

Professionals, Helping or Hindering?

Professionals can also struggle in such existentially shocking situations, especially, perhaps, when we are expected to be 'the experts' at times when we feel as unsure as our service users. These feelings belong to a range of professions. Certainly in *medicine,* as shown in one person's experience following the onset of an increasingly serious and inexplicable paralysis:

> 'I don't want to alarm you … there's nothing to be frightened of… er.. you don't have to worry a wee bit …'. He interrupted himself and turned to one of his colleagues. With words such as alarm, fear and worry thrown in one incomplete sentence, he could not have sought a more dramatic effect! He succeeded in doing precisely what he had been trying hard to prevent: he scared the living daylights out of me! (Laungani, 1992: 13).

Research studies highlight the way *counsellors* are perceived as discomforted and evasive when bereaved clients have tried to tell them about their sense of the continuing presence of the dead (Taylor, 2005) or want to share their spiritual beliefs (Danbury, 1996).

As *social workers*, we will have our own defence mechanisms. Grenier (2005) notes that, when undertaking risk assessments of older people, social workers seek to pin down all the uncertainties, of health, frailty, family support, but avoid confronting the one thing that is certain: the mortality faced by the service user. Perhaps this is linked to the frustration of social workers who:

> may seem, at first sight, to be useless in the face of such remorseless finality … what the social worker might elsewhere attempt to achieve needs not so much to be reversed as set aside … activity and optimism are not required but rather pain and sorrow, even despair … have to be worked with. (Philpot, 1989: 11–12).

Cooper and Lousada relate this quite specifically to the increasing pressure for social work practice to be outcome-led which can lead to 'shallowness in welfare', an avoidance of 'difficult painful, conflictual, affective work' (2005: 7). Yet our strength lies precisely in those moments when 'the suffering of the other connects to our suffering' (Browning, 2004: 29). If this is blocked, put out of our awareness in our daily practice, then social workers cannot be fully present to those who seek us out. Instead we hinder rather than help, seek to look after and reassure ourselves, not our client.

The structure of this Book

Moving on from these broad themes, what follows are summaries of the chapters to show how the discussion will be developed.

Chapter 2; Psychological Theories explores the internal, or intrapersonal of individuals who have experienced loss and how this is categorised: physical/practical, symbolic, psychosocial and with special emphasis on disenfranchised loss. Links are made with the case work tradition within social work. The key theoretical traditions are identified as psychoanalytical; loss and attachment; existentialism and the humanistic school represented by gestalt and their competing and complementary perspectives are explored through their insights into the perceived potency of death and other significant forms of loss, consequently the importance of separating the living from the dead and how the process of separation is posed in terms of the 'stages' and 'tasks' of 'normal' and 'abnormal' mourning. And there is the significance of staying with the intensity of loss and the importance of 'continuing bonds', of 're-membering' rather than dismembering. The case scenarios of *Marcia* and *Kuldip/Kay* are featured,

There is always an interplay between the intrapersonal and interpersonal since feelings are both timeless and rooted in the changing attitudes of the wider society and chapter 3 looks at the social and cultural dimensions whether this is 'death denying' (Ariès, 1981) or a period of witnessing 'the revival' or 'resurrection of death' (Dickinson, 2005, Walter, 2005). Essential to this is today's cultural currency of the 'Good Death' and the contradictory nature of this is illustrated through *Sam,* whose wife's death from cancer confronts him, on many levels, with the stories people tell about dying and how he finds his own voice. The importance of narrative is continued in the scenario of *Dorothy*, who is sought out by the son she placed for adoption which highlights how the changes in our view of children and parenting touches individuals and whole communities.

Chapter 4; Social Work Values focuses on the social work values as they relate to loss, death and bereavement. On the surface, and as expressed in the GSCC Codes of Practice (2002), these seem uncontroversial, nonetheless our values systems, on personal, cultural and professional levels may bring us into conflict situations, not just with our agencies and service users but within ourselves. This chapter explores these dilemmas, as linked to the changing value systems within the profession.

Two themes are identified. The first, *support versus surveillance,* is looked at through the case scenario of Susan and her family, and the *death* of *a baby through a stillbirth.* The *second*, *outcomes versus process,* is seen in the context of *life limiting* and *chronic illness,* specifically Wanda, a child with Cystic Fibrosis.

In Chapter 5; Social Work Skills, methods and theories in work with individuals we acknowledge the growing repertoire of theories and interventions open to social workers in working with individuals. These are discused through the case scenarios of *Lou,* whose now dead husband had Alzheimer's Disease and *Peter* who has enduring mental health problems.

Core issues for social workers are addressed with a special emphasis on assessment, drawing on earlier discussions concerning how we understand loss and ways of working is explored through cognitive behavioural approaches and working with the sense of the self, drawing on psychodynamic concepts. The discussion returns us to the two key themes of the text, the use of narrative and its usefulness in helping us understand the dynamics of disenfranchised loss.

Chapter 6; Social Work Skills, methods and theories in work with families, groups and the wider community continues the emphasis on social work skills and consolidates the learning from previous chapters. The discussion moves from the focus on the individual per se to the wider world they inhabit: family, groups and the wider communities. These are illustrated through previously presented scenarios. The tasks and skills of working with families are explored both through the direct work with the whole family where there has been a stillbirth (Susan, Daniel and the daughters) and the indirect work where an individual service user (Marcia) brings to the social worker's office her experience of her family. The potential of group work is explored through Wanda and her parents as they struggle with a life limiting illness. Working with communities is expanded through the experiences of Lou, an older woman who is widowed and is now finding a new place for herself in the wider world.

Chapter 7; The evidence Base, continues the focus on the reflective practitioner through a consideration of the nature of *evidence* and *research mindedness*, how we can unknow what we think we know, to 'make strange what is utterly familiar' (Reimann, 2005: 90). The chapter examines the competing and complementary arguments about qualitative versus quantitative research, wondering if territorial disputes are actually necessary. The discussion returns to various studies cited in the text, posing questions about methodology, problems and potential and the researcher's value base and also using a particular approach, 'narrative theory' as a case study of how research can nourish the development of new ideas. Finally this writer introduces some of his own work, a small scale study originally focused on the effectiveness of bereavement counselling, to unpack the research process.

The final chapter 8; Social workers within our agencies: the need for 'relentless self-care'

This chapter looks at the degree to which our employing agencies struggle to support and offer containment to their workers. This discussion builds on the insights of Menzies Lyth (1959/1988) into how a hospital sought, and failed, to defend nurses against anxiety, and relates this to social work's experience of stress, and the how this relates to the fear of feeling deep within the culture of modern state welfare (Cooper and Lousada, 2005). The concept of relentless self-care (Renzenbrick, 2004) is adopted and linked to how this might be found within our organizational, professional and personal support systems. Emphasis is given to the importance of supervision and 'the seven eyed model' developed by Hawkins and Shohet (2006) is followed. The chapter ends by revisiting the scenarios and advocating the place of hope in our work.

In concluding this chapter I want to acknowledge the contribution made by previous and present generations of students who have helped shape my views, those peers who have responded to my papers and conference presentations (sections of which have been refined and represented here) and the social workers, practitioners, managers and academics, from a range of settings, who have shared their thoughts, skills and feelings around this work. Above all, thanks to those service users whose stories, implicitly or explicitly, contribute to this study, especially those who did not fit readily into any 'category', those:

> who do not fit our formulae and patterns, the ones who fight us and make life difficult for us. Let us count our blessings for making mistakes, for these are the moments when we get thrown back into chaos and disarray, when we lose our foothold and are forced to stretch beyond already acquired knowledge and insight. (Duerzen-Smith, 1995: 45)

Points for practice

- Most service users that social workers encounter have to deal with loss in some form or another.
- They may have lost a loved one or they may have lost their job, home status, physical or mental health, parents, or child/ren – not necessarily through death but through misfortune.

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- Social workers must therefore be aware of the social and emotional impact of loss and help service users understand how this has affected them and what they need in the way of support.
- Responses to loss are not just experienced internally but will be shaped by the wider society.
- Suggestions might include helping the person to talk about feelings of loss such as anger or grief, linking the person with others who have suffered similar loss, helping the person to maintain positive memories if the loss is of a loved one.