Introduction

No matter where we are in life, we are seldom prepared for death. Over the course of writing this book, I did not ever meet with anyone who, before their diagnosis, had ever seriously contemplated the idea of dying. Thirty-six-year-old Louise had not ever imagined herself having cancer. She told me how, when she was a medical undergraduate, a lecturer informed her class that demographically it was probable that in y number of years, x number of them would be dead. She explained to me:

> We laughed; we thought it was so funny. Quite a few laughed, others shivered. I know at least one has died in an accident, two of us have cancer, various other things have happened, nervous breakdowns, divorces and we have not hit forty yet. No one expects it at their doorstep and we all feel immune from it. Up until it happens to you it is the truth, it always was someone else. Who expects to have a life threatening illness in their thirties?

Confrontation with potentially fatal diseases focuses the mind; it provides an opportunity for values to be reassessed. Priorities are examined and many re-evaluate their commitments and relationships.

The people I met whilst conducting my research were very much individuals. They differed in their reactions to, for example, finding their first symptoms; they responded differently when learning their diagnosis; how they chose to spend the time leading up to their deaths was different too. There were, however, also similarities; their altruistic tendency to defend others from the harsh truth of their actual experience; their increased appreciation of life; their propensity to maximise their capacity to endure and to minimise reports of their physical pain.

In spite of being individuals, we are social beings who live out our lives in the company of others. Long before Auguste Comte ever conceived of sociology as a discipline, John Donne profoundly observed that ‘No man is an island, entire of itself’. As well as being individuals, we are social beings and this book explores not only how the respondents experienced their dying but also the impact they and their experiences had on those around them.

The individuals to whom you will be introduced during the course of reading this book were shocked by their diagnosis, traumatised by this confrontation with their own mortality. However, they hoped for, and indeed deserved, standards of excellence in how their treatment would be managed. Sadly, however, this was not always the case. Ben and Eilish were bewildered by how a series of calamitous human errors resulted in his tragic diagnosis and they found themselves pitched into a political battle between the two senior consultants who were to manage his treatment. On learning her diagnosis, Louise, herself a doctor and mother of two, very young children, was shocked at the callous manner in which her ex-colleague broke the news of her diagnosis, asking her 'What are you crying for?' Rose struggled to contain her emotions when, as the result of a casual question from a radiographer, she discovered that her breast cancer had invaded her brain.

Ben, Louise and Rose lived out their lives in mainstream society. They were people like us. However, the voices of individuals who are dying have seldom been heard. This book aims to open that silence.

The substantive body of this book is the narrative section, which is presented through the framework of four separate stages that combine to form the coherent dying journey. These individual stages can, of course, be explored in isolation as discrete and separate periods, some of which might be experienced also by those who are fortunate enough to recover from their cancer. This narrative is grounded primarily in longitudinal, in-depth interviews held with patients and their carers throughout their dying journey. The accounts are augmented, when appropriate, with field-notes and a brief selection of supplementary studies. Although commentary is provided to highlight motifs and point out themes of particular relevance, the primary intent has been to give voice to those individuals who were in the process of experiencing their dying.

In the many conversations I enjoyed with the respondents, I had a heightened awareness of how they all unconsciously compartmentalised the events they encountered as they progressed through their illness trajectories. Although they did not consciously prompt me into organising their temporal framework into the model I eventually applied, I was, probably not surprisingly, influenced by how they themselves perceived the events to fall. These can be summarised in the four stages I outline below in Table 1.

Although time is an abstract concept into which individuals are socialised (Zerubavel, 1981), those living in contemporary Western life have come to regard it as almost tangible and use it as a form of currency. This can be illustrated by examining how the respondents experienced, especially, the period around the detection and diagnosis of their cancer.

Table 1 *The four stages common to those who are dying from cancer*

Departure	The time of detecting initial symptoms and learning their diagnosis
Exploration	The time of tests and treatment
Anticipation	The time of remission and fear of recurrence
Destination	The time when the imminence of death could not be denied

Stage one charts the events that occurred between the discovery of the symptom(s) and the cancer diagnosis, exploring how those involved first became aware of illness indicators. I examine how contacts were initiated with general practitioners and then consider the earliest meetings with consultants and detail some of the problems that were encountered. The anxiety generated whilst waiting for the results of the medical tests is discussed before I investigate the individuals' immediate reactions on learning their diagnosis.

The individuals with whom I spoke related to that first stage of their illness as though it was as physically real and firmly fixed as a cliff, a boundary marker that explicitly marks the clear division between land and sea. They now thought of specific events in their lives as occurring either before or after their cancer diagnosis. The detection and diagnosis of their cancer marked a '**D**eparture' away from the life they had previously lived in mainstream society and marked the beginning of their journey.

The second stage investigates the events between individuals learning of their cancer diagnosis and settling into their treatment regime. During this difficult time, many struggled to accept the fact of their cancer and to deal with the subsequent changes practically, emotionally and socially. The reality of their illness was, for some, reinforced tangibly as the treatment wrought physical side effects, which had to be confronted and managed: their principal reaction seemed to have been one of complete uncertainty and fear. They had left their familiar mode and temporal pace of life behind and were now attempting to '**E**xplore' and negotiate strange terrain in a time structure that was both unfamiliar and disturbing to them. Still absorbing the shock of their diagnosis, they followed the maps offered by medical science and made their initial connections in the hope that they were not lost. This was not only a time when they were expected to adapt to the requirements and routines of the medical domain but was also when they first began to notice a change in established social relationships.

The third and penultimate stage following the medical treatment appeared for many to be the most difficult. This part examines how the respondents made sense of the liminal time they spent between their remission and the recurrence of their cancer. This was a period when they not only worked hard to maintain a grip on 'normal' life but also struggled with the sense that they had to live up to the heroic role others unwittingly imposed. In many ways, this was the most testing of times, a period marked by gruelling psychological swings between hope and dread.

At this time, their social, and for some, physical identities had already undergone change and they worked to re-establish their previous social status. They craved recognition of their return to mainstream society but this was not always guaranteed. This was a time when they desperately hoped that their cancer would succumb to the treatment but feared it would not. It was a time of '**A**nticipation'. As the captain of a ship, trapped within an ice field, might present a confident face to the passengers on board, so too did the respondents present a positive front to those for whom they cared whilst, in reaction to their inner anxiety, they attempted to pre-empt possible symptoms of their cancer's return by monitoring all and every corporeal change.

Stage four, the final stage, investigates the period around death. By the time the respondents moved into this stage, they were aware that they were dying, they knew for certain that the ultimate '**D**estination' of their journey was death – a premature death. Some contributed to how their death would be managed, for example, by making known their wishes about where the death should occur. Death was now advancing steadily and as its threat became imminent, those who cared for them drew physically closer, valuing the scarce time that remained and guarding it jealously. Those who were still able, both supporters and the individual who would shortly die, worked together to effect as good a death as possible. For many, however, the difficulties of this challenging time were compounded by their lack of familiarity with how dying occurs. This sometimes resulted in a situation where the person who was dying continued to struggle, even in extremis, to maintain control over the event, in their altruistic efforts to protect those for whom they cared.

Beginning with a narrative drawn directly from an interview held with a respondent, just five days before she died, this final stage primarily utilises conversations with the bereaved, who relate how the deaths were experienced by the dying person. To substantiate these accounts, a series of case studies are presented, based on observations in hospices.

The conclusion considers how the individuals you will have met in this book managed the various challenges they encountered during their illness. It explores the role of the everyday dying hero, consolidating Seale's work in *Constructing Death* (1998). It further examines some of the strategies individuals employ to enhance their own remaining time and to ease close relationships that have come under enormous stress.

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Table 2 *Characteristics common to the contemporary dying hero*

Defend or protect others	The respondents all worked on both practical and social levels in their endeavour to defend those for whom they cared from the harsh realities of the experience.
Increased appreciation of life	The respondents all had a heightened emotional appreciation of what they had previously taken for granted.
Endurance of illness	The respondents all tended to endure the psychological and physical aspects of their illness, all of them making practical and emotional efforts to conceal their pain from those for whom they cared.

The degree to which the respondents were socially embedded, enmeshed within their social groups, significantly influenced how they interpreted and managed what was left of their lives. Thus, they handled the various challenges they encountered, interpreting and experiencing the events that they met on an individual level and, therefore, often reacting to them in quite disparate ways. There were however, some specific behaviour patterns to which they did all appear to conform.

The respondents pro-actively engaged in plans designed to diminish something of the practical and emotional difficulties that they believed their illness and dying brought to others. To this end, some made practical provision, for example, negotiating how young children would be cared for after death and organising their own funeral arrangements.

The interviewees, independently of each other, took time to stress how, since becoming ill, they had all learned an increased appreciation of issues, which they had previously considered mundane. They now understood and realised with increasing pleasure the value which underlay the simple things in life, one even commenting on how she had been '. . . woken up to the millions of miracles happening . . . not major ones like stopping wars but the milk being delivered on time . . .'

Despite the horrendous psychological pressures and physical agonies which they endured, in preference to causing those they loved the grief that they knew their death would bring, all preferred to cling on to their lives. Experiencing the physical pain was something only they could do and they often chose to keep the full extent of this suffering private, rather than make it known.

All the respondents in this study, however unconsciously, altruistically attempted to protect those for whom they cared from the pain that they knew their dying would cause.

To summarise, there are three features common to how they managed their illness, set out in Table 2.

For the respondents, dying had become a frightening probability, but they needed to maintain their place in society during the long journey. This book tells us something about how individuals, who had a life threatening disease, lived up to their deaths.

To put their experiences in context, it seems sensible to begin by addressing issues of mortality, exploring how current cultural responses have evolved and shape how death is managed.

1 Mortality in modern culture

Dying is not what it used to be. Temporal changes have seen a movement away from a time when dying was often rapid to a time when a lingering trajectory is increasingly becoming the norm (McKeown, 1976; Ariès, 1974; Walter, 1994). We have shifted away from an era when individuals died secure and confident in their unshakeable belief in an after life to an era when dying is perceived to be an inner journey of the psyche (Kubler-Ross, 1995). We have moved away from a period when death was experienced as part of life to a period when fighting death has turned into the meaning of life (Bauman, 1992).

How have social scientists responded to these transformations in the management of dying and death? Lagging behind the exciting and rapidly accelerating developments in technology, only a few psychological and sociological theories or models (Freud, 1959; Gorer, 1965) were in evidence before, even as recently as the late 1960s.

It may be because of the difficulty many find in countenancing their own mortality that, except for work on demographic aspects, social scientific research concerning death was, until the late 1960s, largely focused on the survivors of death, the bereaved, rather than on those who were themselves dying. Death up to this time was presented almost entirely as though the chief protagonist was the mourner and not the individual most concerned: the person who was dying. Death implied bereavement and not dying; it was about those who survived death. With few, notable, but highly influential exceptions (Kubler-Ross, 1995; Glaser and Strauss, 1964), what work has been contributed tends, for the most part, to be theoretically based. This paucity in sound, empirically sourced work is one which needs to be redressed as present-day mainstream perceptions of dying are influenced less and less by direct personal experience with individuals who are dying, but increasingly by the opinion makers, the academics who formulate theory which is in turn disseminated by the media (Freimuth *et al.*, 1989; Armstrong-Coster, 2001).

Mellor (1993) considers why death remains excluded from mainstream sociology and suggests how this might be remedied. First, he contends, along with others, that death in high modernity has become sequestrated from the public arena. Second, he analyses the privatisation and subjectivisation of death, a phenomenon that, he argues, has been fed, for example, by Kubler-Ross's stage model, which focuses on how death is managed at an individual rather than collective level. Third, he argues that, because sociology as a discipline is so engaged with the project of modernity, it too has sequestered issues of dying and death. He suggests that:

> . . . an adequate integration of death into sociological theory can be achieved only by a partial reorientation of sociology, since sociology itself has been inextricably bound up with the project of modernity. While sociology remains so closely tied to such a project, modernity's systematic sequestration of considerations of mortality will continue to be reflected in sociological theory and practice. (1993: 12)

This point demands a radical revision of the discipline of sociology. Mellor does not call for a total reversal of interest from issues of life to those concerning death; rather he appeals for an integration of both life and death into sociology's core. Should this fail to occur, he argues, then death will continue to be sequestrated both by mainstream society and also by sociologists.

Also promulgated by the media, the seductive philosophies and ethos of the new Hospice Movement, a phenomenon infused with the heartening message of 'good death', have now spread, stretching beyond the confines of the Hospice itself and having informed, have gone on to persuade and pervade general public opinion. The importance of the new Hospice Movement and its philosophies has been and continues to be central to how public attitude to dying and death is shaped.

These two sources then, academia and the media that feeds off it, now inform and educate public opinion on death related issues.

What is the current public stance on issues of mortality? The position of mainstream attitudes has been hotly contested over the years. The United Kingdom is a society that continues to be charged with being 'death denying'. The extent to which this is true has long been at the heart of sociological debate on death (Parsons and Lidz, 1967; Parsons, 1978; Kellehear, 1984; Walter, 1991) but, so far, there has been no satisfactory resolution to that proposition.

What is clear, however, is that the dominance of science has greatly contributed to enhanced standards of living, to a consequent rise in the population (McKeown, 1976) and change in the causes of mortality (Busfield, 2000). We are part of a society living longer and dying more slowly than ever before. The dramatic drop in mortality from infectious illnesses amongst the young means that, increasingly, non-infectious fatal diseases now tend to strike the elderly (Busfield (2000) cites heart diseases, respiratory diseases and cancers specifically). This change in how individuals die has been further affected by the fact that, because of significant advances in medication, death is more inclined to occur after a prolonged period of chronic, rather than, acute illness and, as a result, dying became colonised by the medics (Zola, 1972; Illich, 1976). Consequently, individuals who were dying were subjected to ‘shutting away’ (Ariès, 1974, 1981), ‘cutting off’ (Illich, 1976) and ‘exiling’ (Elias, 1985) from mainstream society.

Countering these pessimistic charges, however, are two facts, which have combined to influence how individuals who are dying are managed. The first is that increasing medical advances together with the initiation, development and growth of specialist Palliative Care services mean that there are more individuals who are living in the midst of prolonged dying trajectories than ever before (Young and Cullen, 1996). The needs of these individuals are at last receiving attention and are in the process of being evaluated and addressed at government policy level.

The second point, perhaps influenced by the first, is that there has been a reversal of clinical opinion. Before 1970, clinicians were reluctant to inform patients of what was viewed, in their opinion, as a dismal prognosis. However, more recently there has been a movement away from that to a position in which people who are dying, as autonomous individuals, are now kept openly informed of their situation (Seale, 1998).

When framed within a society that has embraced the growth of the new Hospice Movement, these two facts render it implausible that death-related concerns continue to be denied but, instead, suggest that they are becoming increasingly aired.

How have these changes come about? Reviewing any development which has evolved over time is difficult: a lens which is appropriate for life in the United Kingdom of the twenty-first century may, with hindsight, judge prejudicially and perhaps harshly, the less advanced conditions of earlier times. However, whichever meter is applied to evaluate the conditions prevalent in the United Kingdom following the Second World War and leading up to the early 1970s, it is indisputable that individuals who were dying were, during those times, considered the ‘failures’ of modern medical science and found themselves marginalised (Thomas, 1980).

Clark’s (1999) authoritative study of the history of the hospice movement (1948–1967) sheds some light on what it was like to die in the United Kingdom in that era. He frames it against the background of the newly developing National Health Service (NHS), a service whose ‘intensely modernising ethic . . . entailed a deep ideological suspicion of charity and which made cure and rehabilitation its clinical goals’

(1999: 226–7). The medical focus was, at that time, on those who could be cured rather than those who could not.

Illustrating something of the plight of those who were dying at that time, Clark draws on an article written in 1948 by W. N. Leak that appeared in *The Practitioner*. Leak argued that a most difficult situation had arisen because 'relatives are not available or willing' to care for the dying at home (1948: 80). Before the Second World War, the decision about where to die rested on the goodwill of a supportive family or in the gift of charitable endeavours. Even those fortunate enough to have relatives disposed to meet the difficult task of nursing them at home were frequently not in receipt of adequate medical care. This situation was aggravated by the fact that, as Leak observed: 'Medical treatment can almost be written in one word – morphine' (1948: 85). Individuals dying slowly in the late 1940s were left in the charge of their relatives and doctors whose knowledge of medication and inclination to prescribe it was often tempered by their own personal beliefs.

For those who were dying without families, other than finding a bed in one of the few charitable homes or religious hospices in existence in this era, the only alternative left was to seek accommodation in hospital. The problem, however, was, as we have already learned, that hospitals were, and still are, institutions whose priority is to provide cure and not nurse the chronically ill: although the physical trajectory of the individuals who were dying was monitored, once considered past cure, they were no longer of interest or concern to the experts. Control and choice were removed from them in favour of the work of the medical teams primarily concerned with patients considered to have some prospect of survival.

This situation was paralleled in the United States, where Sudnow (1967) argued that, at that time (the 1960s), human dignity in hospital was sacrificed in favour of bureaucratic efficiency. Indeed, so far were people who were dying removed from normal ward management that, when a death occurred, other than the basic nursing offices being observed, it was virtually ignored. Individuals who were dying were considered an embarrassment and death was understood principally in negative terms (Thomas, 1980).

It was in an attempt to resolve the problems imposed on the dying by this cultural climate that seeds were germinated which were to become influential in the rooting and consequent flowering of the new Hospice Movement. At this time, individuals who were dying were sequestered and separated, held at a physical remove from mainstream society and psychologically distanced from the staff caring for them (Gorer, 1965). Such situations prompted Swiss physician, Elisabeth Kubler-Ross, to