

Chapter 1

Palliative and End of Life Care for Children and Young Adults

The death of a child at any age and from any cause runs against the natural order (Milo 1997); indeed there is something profoundly 'wrong' about a child predeceasing its parents. As Sourkes (1977: 65) argues, the 'assumed sequence' is thrown out of order; parents who would have expected their children to care for them at the end of life instead find themselves witnessing the 'tragic absurdity' of watching their child die.

Although across the world incurable illnesses claim the lives of children on a daily basis, the culture of modern Western society tends to 'push awareness of these personal tragedies to the back of our minds' (Riches and Dawson 2000: 9). Death and illness are hidden from view in a society where most acute illness and the majority of deaths are managed out of sight in hospitals and hospices. As a result, family members engaged actively on a daily basis with the care of a child with life-threatening or life-limiting illness can feel isolated in a world hidden from view. Their struggles may remain unobserved and they can find it difficult to access the support needed for the child, siblings and their own welfare.

Benini et al. (2008) define 'life-limiting' conditions as those where a premature death is usual and these would include such conditions as Duchenne muscular dystrophy (DMD) and a variety of chromosomal disorders. However, although a 'life-threatening illness' carries a high risk of premature death, there is also a chance of the illness being cured and it is usually this term that is applied to cancer diagnoses. According to ACT (2011a), there are at any given time more than 23,000 children with life-limiting or life-threatening illness in the UK, half of whom will have substantial palliative care needs. Approximately 80,000-100,000 family members and carers are involved in the support of these children, whose needs may be complex; thus, in the UK alone there are significant numbers of individuals with the potential to feel alone and isolated. Indeed, almost by definition, the families caring for a child with complex and life-limiting health problems are likely to become socially isolated as a result.

Runswick-Cole (2010: 813) claims that services for children with life-limiting illnesses have been poor, but there has been little research in this area because of what she calls the 'wider social embarrassment' of talking about death and

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the need to distance disability from the 'tragedy stories' of the past. Her findings suggest that families experience both social isolation and poverty, lack appropriate support and worry about the costs of care. However, the recent increasing recognition of the challenges faced by both families and professionals caring for a dying child has resulted in a number of policy documents and academic texts - many of which are cited here. What this book adds to a growing body of literature is the voices of the people charged with the care of children, teenagers and young adults whose lives are coming to an end. The following chapters draw upon in-depth interviews with both professionals and family members in order to understand what it is like to care for a child who will die.

The topic of palliative and end of life care for children and young adults is so wide that some boundaries have had to be drawn to structure both the data collection and the remit of this text. Consequently, the book is based mainly on data derived from two studies, one looking at the specific issues relating to cancer in teenagers and young adults, the other an evaluation of children's hospice services. The contrasting experiences of the two cohorts results in some fundamental differences in the nature of the data collected. The use of health care services, the type of services used, the length of time care may be palliative and the transition between palliative and end of life care, may vary considerably according to the type of condition with which a child is diagnosed. This means that the empirical chapters that focus on a particular health care setting reveal very different types of experience and usage within that setting. Not all issues will be relevant to both cohorts, but the contrast becomes part of the analysis.

It is hoped that such a comparison will be beneficial for those planning services by answering such questions as: what are the similarities and differences between children born with a life-limiting condition and young people diagnosed with acute life-threatening illness in adolescence? When do services need to be separate? What are the contrasts in the families' experiences and needs? In addition, drawing on the accounts of both professionals and families allows the perspectives of each to be heard, and for the complex dynamic that operates in such a highly charged and often distressing context to be better understood. Quotations and case study material from in-depth interviews have been selected to provide examples that give an insight into what it is like to support children and young adults at the end of their lives. The quantity of original qualitative data that acts as the basis for this book amounts to some 400,000 words, thus it is impossible to do justice to each and every transcript, but readers can be secure in the knowledge that, through the process of analysis, the full range of experience has been represented and that claims made in the text are based on a wealth of data that remains largely unobservable. Although individual participants' stories have been selected to represent the wider data set, I have tried to remain true to the spirit of all those who participated in the research and represent the range of views, opinions and experiences.

The book begins with an overview of the literature and policy in the area and then moves on to present chapters based on the firsthand accounts of the participants. There are chapters on palliative and end of life care as it is

experienced in the home, in children's, adult and adolescent hospices and in hospitals. These are followed by a chapter on how parents and professionals manage communications with the children and young people about end of life and how they negotiate the transition from curative to palliative treatment. This chapter also considers the bereavement needs of the parents, how they can best prepare themselves for their loss and how their grief and loss may be shaped by the way in which end of life decisions were made and shared - or not - with their lost children. Drawing on the analysis of the empirical data, the final chapter considers the implications for policy and practice. The appendix includes an account of the methods used to gather the original data on which the empirical chapters are based.

Defining palliative and end of life care

This book addresses both palliative and end of life care. The boundaries between the two may be blurred and some of the young people whose stories are told in this book were in receipt of palliative care while also receiving active treatment; in some cases the palliative phase was brief, in others it continued for years. It would therefore be helpful to define the terms. Clark and Wright (2003) provide a summary of the World Health Organization's (WHO) definition as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of the illness
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(Clark and Wright 2003: 1-2)

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This definition makes it clear that palliative care may mean 'end of life care' but can also be used in conjunction with active treatments that may prolong life and can be utilised as a strategy early in an illness to relieve suffering. In a slightly different use of terminology Benini et al. (2008) say that although terminal care is not the same as palliative care, palliative care can include terminal care; this distinction they say is crucial as it can establish eligibility criteria in a field where they claim that a minority of children across Europe benefit from palliative care.

The definition of end of life care offered by Kirsti and Dyer (2006) suggests that the precise definition of 'end of life' is problematic:

There is no exact definition of end of life; however, research supports the following components:

1. The presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and
2. The symptoms or impairments resulting from the underlying irreversible disease that require formal either paid, professional or informal unpaid or volunteer care and can lead to death.

End of Life Care

End of Life Care is the care provided to a person in their final stages of life. Also known as hospice care, comfort care, supportive care, palliative care or symptom management.

(Kirsti and Dyer 2006)

So it seems from this definition that 'palliative care' has been subsumed into 'end of life care'. Field and Behrman (2003: 34) suggest that 'end of life care' has no precise meaning but is used to describe the care that focuses on the preparation for a death that is anticipated. Field and Behrman also say that, together, palliative and end of life care should promote clear and culturally sensitive communication in order to help patients and families understand the diagnosis, prognosis and treatment options available.

Challenges to the delivery of palliative and end of life care for children and young people

This book addresses issues of both palliative and end of life care, thus it encompasses the care that may be given to children and young people with life-threatening and life-limiting illness perhaps for some considerable time before the end of their lives. This is particularly true of the children and young people who have been born with or develop a chronic condition in early childhood. They may in fact use palliative care services for the whole of their lives, whereas, in contrast, the teenagers and young adults (TYAs) diagnosed with cancer will undergo an intensive phase of treatment with the aim of cure. For those TYAs diagnosed with cancer who are not cured,

their period of palliative care may be much shorter and raise different issues and challenges.

The European Association of Palliative Care (EAPC 2009) states that although access to palliative care for adults with incurable conditions is regarded as a right, the provision for those in the paediatric age group is still in its early stages and services for children and their families are fragmented and inconsistent. The reasons given for this are that the numbers of eligible children are fewer in comparison to adults, there can be a gap in organisational and managerial policy, a shortage of competent medical staff and cultural issues relating to the care of dying children that affect social acceptance. This is echoed by Price and McFarlane (2009) who say that difficulties arise from the differing needs of children and families, the variation in the availability of services and a lack of understanding by policy makers as to what constitutes palliative care.

Benini et al. (2008) also suggest that symptom management at the end of a child's life can be inadequate and that, along with clinical problems, the psychological, social and spiritual aspects may receive inadequate attention. These authors suggest this is a global problem, that insufficient resources are dedicated to this area of medicine and geographical location may affect access as may disease type.

The Department of Health (DH) policy document 'Better Care: Better Lives' (2008) identifies a number of challenges to the delivery of palliative care for children including:

- The change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies
- Poor co-ordination of services across the statutory and voluntary sectors, particularly transition between children's and adult services
- Little acknowledgement of the need for earlier interventions and assessments
- Insufficient investment in local prevention strategies or timely referral to specialist services
- High thresholds/eligibility criteria for accessing existing palliative care services
- Insufficient prioritisation for children with life-limiting or life-threatening conditions, and short term funding
- Lack of transparency/agreement between budget holders about who will fund which aspect of care and support
- Lack of capability, capacity and equity within universal services to meet many of the needs of these children (and related workforce issues, including shortage of specialist staff)
- Lack of information, consultation and empowerment for children with life-limiting or life-threatening conditions and their families
- The need for a range of specialist short breaks which would include breaks in the home, in children's hospices and the other voluntary sector providers, as well as better co-ordinated specialist support.

(DH 2008: 15-16)

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Thus, it can be seen that although there is recognition of the increasing need for children's palliative care services, there are a number of problems associated with its widespread provision and its availability to all children and families in need of such support.

In order to address the issues raised above and to provide high-quality services to children with life-threatening and life-limiting conditions and their families, the DH (2008) state that palliative care should form a thread throughout the lives of these children and that palliative care needs to be high on the agenda of those responsible for the provision of children's services. To achieve this, the DH identified eight strategic development goals, which are:

- Improved data
 - Equality of access to universal services
 - Responsible and accountable leadership
 - Choice in preferred place of care and expansion of community services
 - Better end of life care
 - Stronger commissioning and value for money
 - Successful transition between children's and adult services
 - Planning and developing an effective and responsive workforce
- (DH 2008: 18)

The needs of families and children include physical, psychological, social and spiritual care, and the Department of Health policy document 'Better Care: Better Lives' (2008) recognises that families who have the responsibility of caring for a child with life-limiting and complex conditions need to be supported. The report also recognises that families need a more personal, community-based service where agencies work together. Continuity of care is also important so that in times of crisis the professionals caring for their child are known and trusted.

Settings of care

As Brook et al. (2006: 533) argue, the palliative care journey from diagnosis through to bereavement, presents many problems. If the primary objective is to support the child and family, the care provided should be tailored to their needs. However, flexibility is necessary as these needs can change over time; the birth of a new baby, the illness of a sibling perhaps from the same condition, bereavement, divorce and other life events can all affect the provision of care.

Bearing in mind these changing needs, there are a number of settings in which care can be delivered. Many young people will be cared for in their homes for much of the time. This, Brook et al. argue, can reduce the disruption to family life, be beneficial to siblings and may be the preference of the sick child. Similarly Hynson (2006) reports that many families describe home care as positive, subject as it is to fewer interruptions and intrusions. Feudtner et al. (2007) claim that since 1989, children with complex, chronic conditions are increasingly dying at home as a result of evolving epidemiology, advances

in home-based medical technology and changes in attitudes. Nevertheless, end of life care at home can present challenges and Hynson reminds us that it is not desirable for all families. But even those families who choose to support end of life care at home may be ill-prepared for the demands; as Contro and Scofield say (2006), they can be required to perform care-giving tasks they had not anticipated. These issues and experiences are addressed through the firsthand accounts in Chapter 2. Home-based outreach care provided by hospices is also considered in this chapter on home deaths rather than being included in the chapter on hospice deaths.

Chapter 3 examines the difficulties of providing hospice care. In the UK 'hospice care' is taken to mean care within a hospice building, whereas in the USA it has a different meaning and encompasses a philosophy of care that is usually delivered in the home rather than in an inpatient facility and the term can be used to cover all palliative care (Brook et al. 2006: 542). This book uses the UK interpretation of hospice care. Brook et al. establish that only 20% of children who use hospice care die in a hospice, although they can be transferred from a hospital for hospice care when the end of life approaches. The challenge for hospices in providing care - particularly transitional care - is addressed in Chapter 3, in which the differing roles of paediatric, adolescent and adult hospices are considered through accounts from both families and professionals.

Children's end of life care may also take place in hospital, indeed the majority of all child deaths in the UK and the USA occur in hospital (Brook et al. 2006: 542). Of these deaths 60% are due to complex, chronic life-limiting conditions. Although the majority of childhood cancer deaths occur in the home - Brook et al. cite UKCCSG figures of 78% - where the death is a result of the complications of curative treatment, these deaths tend to take place in hospital. The majority of children who die in hospital do so on a paediatric intensive care unit (ICU). Brook et al. (2006: 541-542) claim that much can be done to establish a 'home from home' environment in hospital. In addition, the provision of shared care between a primary treatment centre (PTC) and a local hospital can allow a child to be treated nearer to home and where this is not possible family accommodation may be provided. Yet, according to these authors, families continue to report 'confusing, inadequate or uncaring communication' and feel that they have lost control. The bereaved families of children who have died from cancer in hospital also report greater guilt, anxiety and depression than those whose children die at home. The experience of hospital deaths is considered in Chapter 4; however, many of the empirical examples in this chapter relate to young adults with cancer whose hospital care at the end of life can be particularly complicated to organise.

Transition from paediatric to adult care

The age range covered in this book is wide, including children, teenagers and young adults. Thus, the age band encompasses the transitional stage between paediatric and adult services when, as a result of their age, young people may

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find themselves cared for in inappropriate environments. As more young people are surviving life-threatening and life-limiting illnesses into adulthood they need to make the move from children's services to adult services (DH 2008, Marsh et al. 2011). However, a seamless transition is difficult to achieve if there is a gap between services that results in the young person remaining too long in an unsuitable paediatric environment or being transferred too soon into an adult care setting with older people. Where close relationships with paediatric staff have been developed both by the young people and their families, the move can seem a particularly daunting prospect. Thus, successful transition from children's to adult care involves careful planning in order to ensure a seamless process. To achieve this, the DH (2008) suggests that it is important to:

- start early
- be flexible
- be individually tailored to meet the needs of the young person and their family
- continue, if necessary, following the transfer to adult care (DH 2008: 40)

The co-ordination of transition is crucial and a key/named worker or lead worker should in ideal circumstances be identified to oversee the process (DH 2008). This should ensure links between the services. The Association of Children's Palliative Care (ACT) Transition Care Pathway provides a framework (2007). ACT acknowledges that there is a wide variation of services across the country but identifies key principles for the move to be successfully managed. These include for young people:

- specific service provision
- development of skills of self-management and self-determination
- supported psychosocial development
- involvement of young people
- peer involvement
- support for changed relationships with parents/carers
- provision of choice
- provision of information
- focus on the young person's strengths for future development

For parents:

- support for adjustment to changed relationships with young people
- parental involvement in service planning
- a family-centred approach
- provision of information (Association of Children's Palliative Care 2007: 10)

The documents cited provide a framework for the provision of palliative care for children and young people, and their recommendations act as a useful

context for the consideration of service provision for the age group. However, they suggest that although the need for appropriate services has been recognised as an issue of significance, there is currently inconsistent provision. Craig (2006) argues that it can be difficult to identify the most appropriate team to take on the care of an adolescent and that in addition paediatricians may be reluctant to let go of their patients and allow them to move to adult services.

The problems of transition are summarised by the subtitle of a Report on the issue prepared by Marsh et al. (2011): *Small numbers, huge needs, cruel and arbitrary division of services*. Marsh et al. (2011: 6) argue that 'there is **no clear model** of care underpinning services' and that professionals:

live in silos, locked into separate and differing assumptions, structurally separated systems that are Children's and Adult services ... **have few means of sharing insights into each other's work** and culture and find it difficult to identify and adopt good practice ... **struggle to operate transition planning procedures** ... and '**work around**' **dysfunctional systems**. (Original emphasis)
(Marsh et al. 2011: 6)

Marsh et al. claim that young people's experience of transition is poor both in terms of the services provision and their level of autonomy. Parents too, according to these authors, have a poor experience in terms of the impact on their son or daughter and on themselves as there may be fewer opportunities for respite care. Suggestions for how the system could be improved include:

- a **broader support system**, taking on the social issues raised by young people
 - a continuing **clear clinical lead** role
 - **cross system networks**
 - **young person-centred** ethos
 - **joint** training and development
- (Marsh et al. 2011: 8, original emphasis)

These transitional issues and the extent to which the recommendations made by Marsh et al. are already recognised or in place, are addressed throughout the book.

Children and young adults with cancer and place of death

Despite the wide range of illness from which children and young people die, neoplasms are the main medical cause of death for 1-24-year-olds (National Cancer Intelligence Network 2011), thus it is important that we have some notion

Table 1.1 Descriptive statistics for cancer deaths registered in England and Wales in 1995–9 for children and adolescents (age range 0–15) and young adults (age range 16–24). Values are numbers (percentages) unless otherwise indicated.

Place of death	Children and adolescents (0–15 years, n = 1725)	Young adults (16–24 years, n = 1472)
General hospital or multifunction site	43	58
Home	52	30
Hospice	3	9
Other	2	3

Extract from Higginson and Thompson (2003: 478). Reproduced with permission from BMJ Publishing Group Ltd.

Table 1.2 Percentage of deaths 1998–2002.

Place of death	0–13 years	14–24 years	25+ years
Hospital	28	37	33
Home	30	23	21
Hospice	7	5	8
Unknown	35	35	38

of where children and young people die from malignancies that are the biggest single cause of non-accidental death. Based on an epidemiological study of 3,197 children and young people with cancer, Higginson and Thompson (2003) noted that there are a relatively high proportion of home deaths (Table 1.1).

Yet we can see that the proportion of home deaths is higher for children (52%) than for young adults (30%). Moreover, as Higginson and Thompson comment, 'This is higher than for the United States (20%) and for adults (26%)'. It is also evident that very few children or young adults died in hospices as might have been expected. The reasons for these apparent anomalies may be accounted for through the empirical data in this book and are the subject of discussion in the following chapters.

In 2010, The North West Cancer Intelligence Service (NWCIS) prepared data on place of death on [my] request. A summary of these data for the North West Region of the UK from 1998 to 2008 is given in Tables 1.2 and 1.3.

What is perhaps most surprising is the percentage of 'unknowns', where the location of death could not be identified. This means that the data have to be treated with some care. However, we can see that the figures are relatively consistent across the 10-year period, suggesting that services have not developed or changed significantly during that time. What is more important is that

Table 1.3 Percentage of deaths 2003–2008.

Place of death	0–13 years	14–24 years	25+ years
Hospital	34	40	41
Home	28	29	23
Hospice	10	6	9
Unknown	28	25	25

the percentages for the places of death for young adults (14–24 years) are in the same rank order as those reported in the Higginson and Thompson study: hospital, home, hospice.

A later briefing from the National Cancer Intelligence Network (NCIN) (2011) offers figures for place of death for children, teenagers and young adults who died from cancer in England between 2000 and 2009, during which time 2611 young people died before the age of 15 and 2975 died between the ages of 15 and 24. Although survival rates are improving, with more than 78% surviving at least 5 years after diagnosis, cancers are still the main medical cause of death for 1–24-year-olds. The NCIN figures show that of the children: 47% died in hospital, 39% in their own home, 11% in a hospice or specialist palliative care unit (SPCU) and 3% in a care home. However, for the teenagers and young adults: 52% died in a hospital, 32% in their own home 13% in a hospice or SPCU and 3% in a care home. Again, we have the same rank order for place of death.

The NCIN study shows that deaths from leukaemia or lymphoma were more likely to take place in hospital, whereas the patients who died in a hospice or SPCU were more likely have bone tumours and soft tissue sarcomas, although the highest proportion dying in their own homes had bone tumours. The data also suggest that place of death was more likely to be in a hospital for Asian patients than for White patients. In summary, children were less likely to die in hospital than teenagers or young adults, and ethnicity and socio-demographics are also likely to have influenced place of death.

Although statistics on place of death give us some idea of where children and young people with cancer die, we can gather little about how – or even if – a choice was made or what the experience was like. However, there are a few studies that address the more qualitative issues surrounding end of life care and place of death. For example, according to Contro et al. (2002), families tend to be dissatisfied with communication with health professionals at the end of life and feel that their wishes are disregarded. Montel et al. (2009) argue that such communication difficulties with health professionals or within the family are factors that are likely to interfere with choice of place of care at the end of life.

The first study on place of death for young adults with cancer in France was carried out by Montel et al. (2009), who claim that theirs is also the first study to examine the factors that influence the choice of place of death in this age

group with cancer. As these authors say, it is essential to carry out such research in order to meet the needs of the young patients and their families at the end of life. Of the 21 young people in the study, 19 died in hospital and only two at home. Montel et al. attempted to identify the determinants of choice of the place of death. Ninety per cent of the families said that they had not felt that they actually 'chose' the place of death, but would nevertheless have chosen the hospital where the death did in fact take place, had they had a choice. Thus, they were not expressing dissatisfaction with the service but with their lack of options.

Only three out of Montel et al.'s sample of 21 were informed about the palliative care mobile unit, but were as a consequence enabled to support a home death. Nine of the sample were given information about the existence of home hospitalisation. Motivations for the 'choices' made were, according to Montel et al., as follows. There is a desire to keep the child at home for as long as possible to retain normality and to be surrounded by family and friends, and most of the young people wished to stay at home for as long as possible. However, some parents felt that home care signalled the end of curative treatment and thus confirmed the approaching death of their son or daughter. Others believed they would have to leave a home where their child had died as the memories would be too painful and that the medical invasion of their home would be a negative experience. The protection of siblings from proximity to the death was also an issue.

The choices available to families and young people about place of death is a theme that runs throughout this book for both the TYAs with cancer and the children with other complex and life-limiting conditions.

Preparation for bereavement and bereavement support

The bereavement support after a child's death is, according to Lenton et al. (2006), an integral part of palliative care. Lewis and Prescott (2006) also claim that such support should be available at whatever age a child dies under whatever circumstances and in whatever setting. There should be a range of flexible and sensitive services that extend to the wider family if necessary as well as to the dying child. Preparation for bereavement is also an essential part of this process as Contro and Scofield (2006) state, most parents say they would have benefited from more preparatory information.

However, although preparatory information may be important, so too is an element of control at the end of life in terms of preparing for how and where the death will take place. Dussel et al. (2009) undertook a study of 140 bereaved parents of children between 1 and 10 years old in the USA, and discovered the longer term effects of having the opportunity to plan the place of death. This study found that in those cases where the treatment options had been explained clearly at the end of life, there was a greater likelihood of planning for place of death. Ninety-seven per cent of the parents who planned their child's location of death also reported that their child had actually died in their chosen setting.

Planning was also associated with parents feeling more prepared for the death, experiencing less invasive care and having fewer regrets after the death. Dussel et al. suggest that experiences at the time of death have a lasting effect and that planning may affect long-term bereavement outcomes. According to these authors, although death at home might be preferred by many, the actual location of death (LOD) may be less important than is assumed, as, among the attributes of a good death, dying at home was the least important. These authors acknowledge that their sample was mainly white and middle class and suggest that there may be ethnic and racial differences.

Even when the death of a child has been expected, the actual death is still profoundly shocking, an unparalleled agony likened to an amputation (Thomas and Chalmers 2009). According to these authors, poor bereavement care can exacerbate and prolong families' distress, whereas sensitive and appropriate care can help families grieve; they too emphasise the need for bereavement care to be an integral part of palliative care.

Thomas and Chalmers (2009) argue that there is a need for professionals to examine their own beliefs and values relating to death and dying, yet it is also important to remember that when planning bereavement services and support, the culture and ethnicity of the families need to be taken into account. Brown (2006) argues that ethnicity and culture profoundly influence how families experience death. She claims that over the last two decades there has been an increasing awareness of the importance of listening to parents and of the need to avoid stereotypes concerning the level and nature of support that would be welcomed by families. Thus, information about different faiths and cultures is only relevant if it is meaningful to the families concerned. Although this book does not include examples of deaths in families from ethnic minorities, Brown's claim that families need to be heard and responded to on an individual basis that is meaningful to them is still very relevant, as there can be a tendency to implement a model of grief as the basis for post-bereavement services without taking into account the individual and differing needs of families. These issues are addressed in Chapter 5.

Summary

So what do we know about how and where young people die? It is clear that there is a great deal of literature on the topic and a number of policy documents that address many of the issues and difficulties. Yet there is still much that remains unknown as the statistical data provide a restricted understanding of the experience. As Benini et al. (2008) say, there are no published data on the incidence of life-limiting and life-threatening illness in children for most countries in Europe. Even where there is information on service provision that includes statistics on hospital, home and hospice deaths, this nevertheless tells us little about what choices were offered and raises the following questions. Did the setting of palliative and end of life care and place of death reflect the families' and children's wishes and preferences,

or was there no option? How were those settings experienced? Has the increasing recognition of the challenges of transition translated into improved services? Were professionals and parents able to discuss their child's death with them in advance? These questions are addressed in the remainder of this book, drawing primarily on research with health professionals, parents and some children who use the services. Through their accounts we can chart the challenges for service providers and the difficulties faced by the children and their families in obtaining appropriate care.