

Living and dying with dignity

The best practice guide to
end-of-life care for people with
a learning disability





“Some people in other services are as scared of learning disability as we are of people dying... so it’s about breaking the barriers down.”

A learning disability nurse

“There is a need for patients with a learning disability to be given access to the same services providing specialist palliative care as other individuals.”

A parent

About the authors

Sue Read

Sue Read, PhD, M.A., RNMH, Cert.Ed. (FE), Cert. in Bereavement Studies is a Reader in Learning Disability Nursing at the School of Nursing and Midwifery, Keele University, Staffordshire, UK. She has worked in the area of learning disability since 1976. Her PhD involved developing a unique, specialist bereavement counselling and support service for people with a learning disability in North Staffordshire. She is an international speaker, and has written numerous publications around loss, death, dying and end-of-life care, particularly in relation to people with a learning disability. She is the editor of 'Palliative Care for People with Learning Disabilities' which is published by Quay Books. She is currently working on a collaborative research study with a colleague (Dr. Stuart Todd, Glamorgan University) to explore perceptions of death and dying with people with a learning disability. Her most recent book is a bereavement counselling manual for people with a learning disability, available from Quay Books, London. She worked with members of Mencap to submit the project bid and acted as consultant to the North Staffordshire Palliative Care Project.

Heather Morris

Heather Morris RNMH, DN, BN (Hons) Palliative Care, has worked within learning disability services (private, statutory and charitable) since 1988. Prior to this project, Heather was the co-ordinator of the Mencap Sharing Caring project based in Stoke on Trent. She co-authored a chapter in the book 'Palliative Care for People with Learning Disabilities' (Read, 2006) with local clinicians. She has had an interest in end-of-life care for many years, worked with members of Mencap and Keele University to submit the project bid and became the co-ordinator of the North Staffordshire Palliative Care Project.

Acknowledgements

The authors would like to thank Mencap for believing in the importance of this work and facilitating its development; and the Donald Forrester Trust and the Big Lottery Fund for financially supporting the work and making the dream become a reality.

Working with death and dying is rarely easy, but working alongside people with a learning disability, their family, friends and other professional carers although challenging and emotional, reminded both authors of what remains important in life. Family, friendships, relationships, people, good health and good deaths are the cornerstones of life.

We wish to thank all of those people we met along this short journey; who shared their lives (and deaths) with us and made the project so worthwhile. We are indebted to these people who invited us into their lives; who unselfishly allowed us to learn from their experiences and allowed us to share our learning with others. The numerous health, social (statutory and voluntary) professionals involved remained supportive throughout the project and contributed to the growing debate around this sensitive area of care. Without all of these people this best practice guide simply would not have been written.

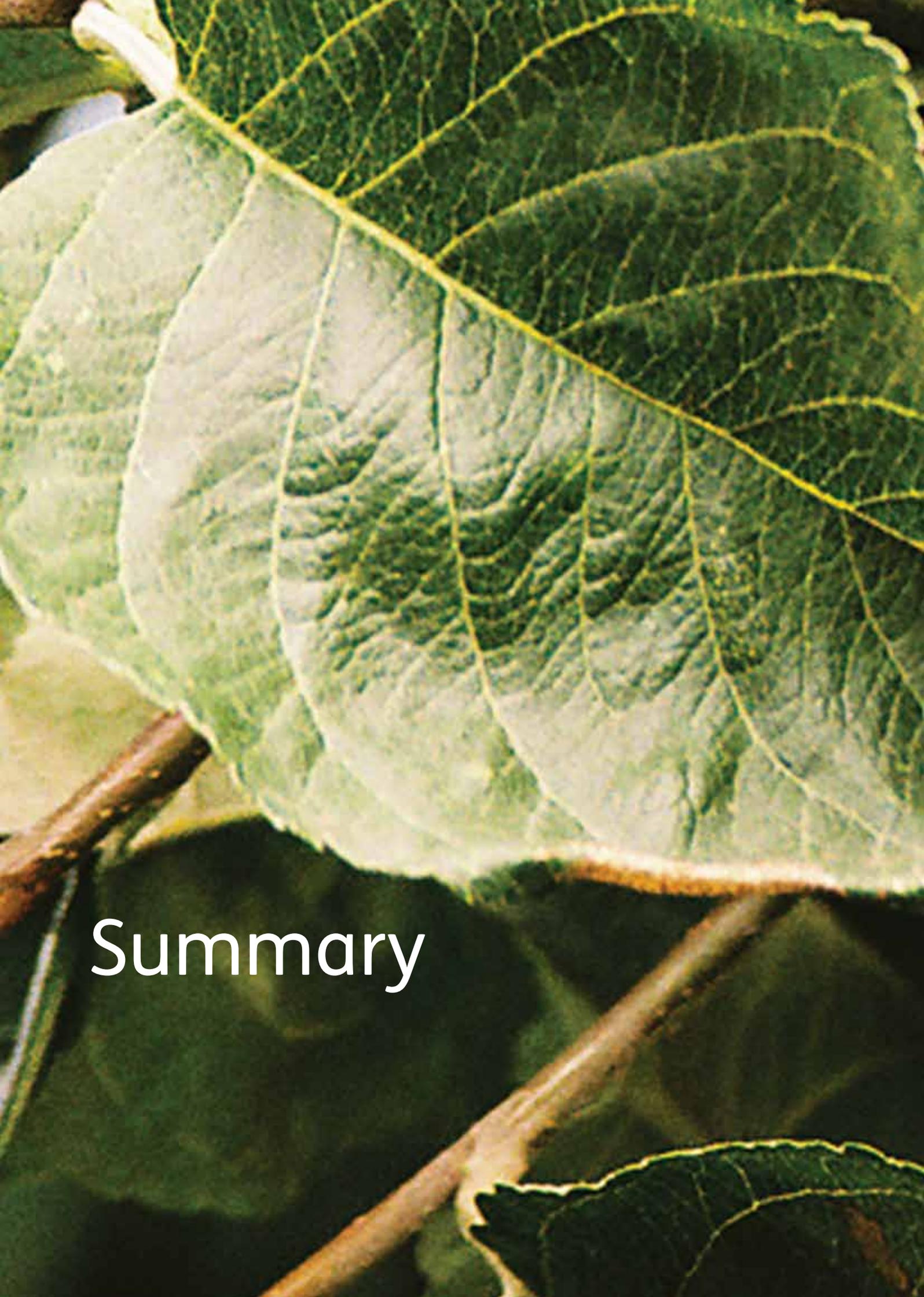
Thank you.

Sue and Heather
7 November 2008

Contents

Summary		7
Chapter 1	Introduction	10
	Background to the project	
	People with a learning disability	
	Gathering information	
	A national perspective	
Chapter 2	Persistent challenges to accessing end-of-life care for people with a learning disability	17
	Health needs and health access	
	Communication	
	Communication: symptom recognition	
	Communication: assessment	
	A carer's perspective	
	Disenfranchised dying	
Chapter 3	Recognising when someone is ill	23
	Signs and symptoms to look out for	
	Getting help	
Chapter 4	Getting expert help	26
	Diagnosis and prognosis	
	When the news isn't good	
	People who might be able to help (client and carers), and places where help is provided	
	Circle of support	
	Care pathways	
Chapter 5	Holistic end-of-life care for people with a learning disability	34
	Holistic care	
	Holistic care for people with a learning disability	
	Facilitating holistic care	
Chapter 6	Promoting autonomy and choice	37
	Involvement (disenfranchised dying)	
	Autonomy and choice	
	Capacity and consent	

Chapter 7	End-of-life issues: Preparing for death	42
	Preferred priorities for care	
	Making a will	
	Saying goodbye	
	Support for people who have a learning disability	
	Support for friends, family and carers	
Chapter 8	Coping with loss	48
	Bereavement as loss	
	Responding to death	
	Challenges to bereavement support	
	Disenfranchised grief	
	Facilitating grief: a creative approach	
Chapter 9	Challenges to be considered: a proactive approach	54
	Health promotion: ideas for the future	
	Collaborative working	
	Develop links	
	Research: the route to good practice	
Chapter 10	On reflection...	63
	Resources, publications and references	65



Summary

There are 1.5 million people with a learning disability in the UK. They are among the most excluded and disadvantaged people in today's society, particularly where issues of health and end-of-life care are involved. This guide is written to support those health, social care, voluntary and statutory care providers and deliverers, either in the learning disability or end-of-life care field, who may be involved in caring for a person with a learning disability at the end of their life.

This guide is the outcome of a two-year project in North Staffordshire (funded by the Big Lottery) in which Mencap and Keele University worked collaboratively to support individuals with a learning disability, their family and carers through their journey to the end of their life. The guide was written based on the authors' experiences throughout the project, and the contents dictated by the outcomes of focus groups and numerous dialogues with a range of parents, carers and health and social care professionals. Case illustrations are used throughout to ensure that the guide remains grounded in practice so that theory can relate to practice in a meaningful way. Once written, the draft guide was circulated to parents, carers, nurses, representatives of voluntary organisations, and various professionals in learning disability and end-of-life care services, across the UK for feedback. Much of this feedback was integrated within the final document.

Chapter one provides a context to the guide; a backcloth against which the project was developed and how the guide was produced. **Chapter two** reflects on the persistent challenges inherent in accessing end-of-life care for someone with a learning disability, with a focus on communication issues.

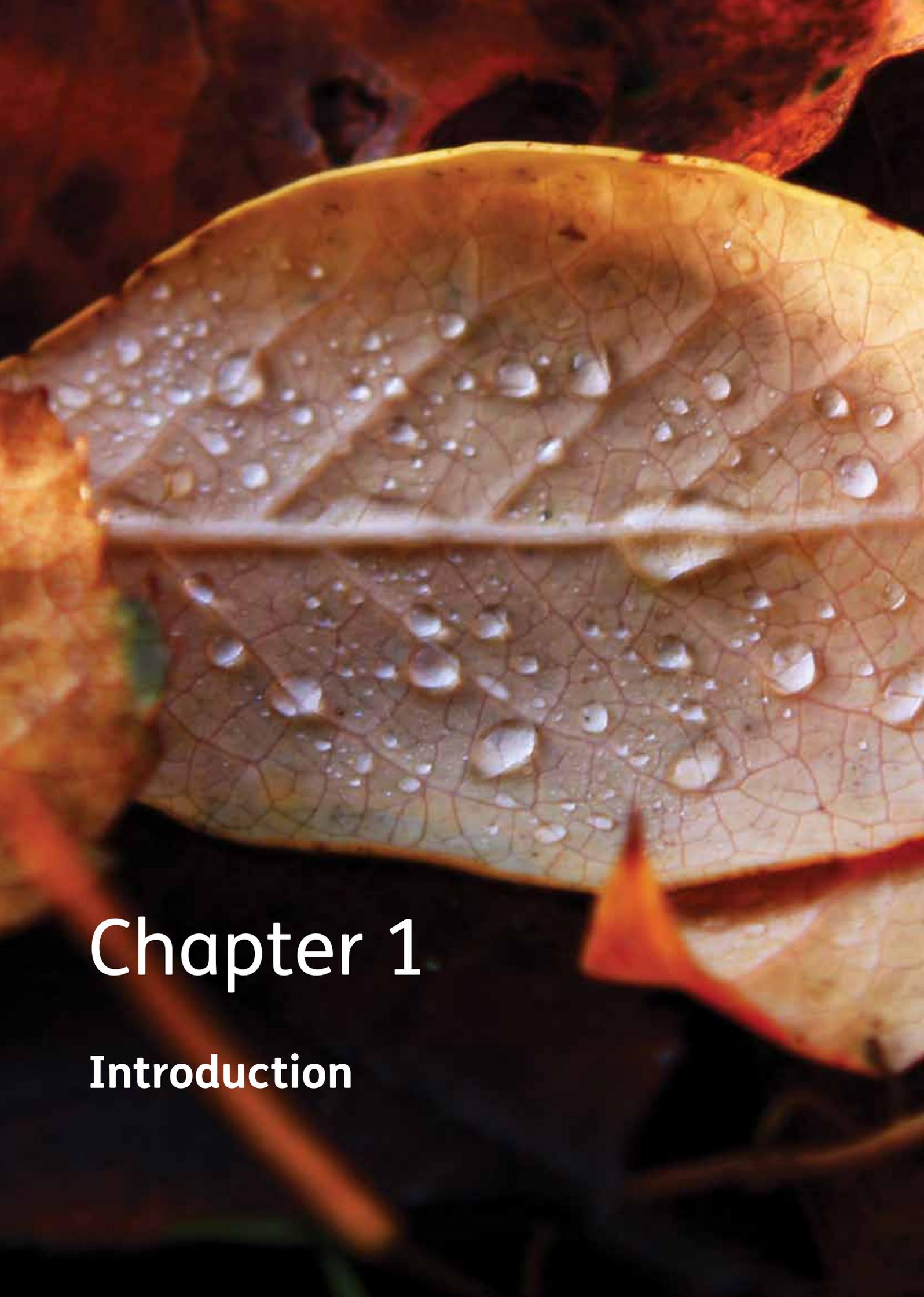
Chapter three recognises that people with a learning disability may not be able to spot ill health, and introduces ways for professionals to notice changes indicative to potential ill health. **Chapter four** focuses upon where and how to access specialist care and support, with the person remaining at the centre of care. Issues around breaking bad news are explored here.

Chapter five explores the concept of holistic care and support, introducing the importance (and challenge) of spiritual support as a key dimension of holistic care. **Chapter six** promotes the importance of actively involving the dying person in care and treatment options, promoting autonomy and choice and minimising the potential for disenfranchised death. **Chapter seven** embraces the potential for providing a 'good' death; encouraging carers to explore issues such as preparing for death, making a will, and saying goodbye to families, friends and loved ones, with the person who has a learning disability.

Chapter eight deals with the aftermath of death, providing ideas to constructively support the bereaved person with a learning disability as they come to terms with their loss and seek ways to both accommodate and commemorate their loss. **Chapter nine** seeks to anticipate the future challenges from a practice and research perspective. This section also incorporates a checklist for positive practice – this may be useful from both learning disability and end-of-life care perspectives. **The final chapter** is a short reflection by the authors around the development of this best practice guide and the journey throughout the project. The resources and references sections contains useful supportive resources for

anyone involved in this area of care. The 12-point reference booklet is a succinct reminder of the key issues that can help to promote better end-of-life care for all people with a learning disability.

While this guide provides knowledge and information, and raises ideas that may challenge current practice initiatives, it was never intended to replace education and training around this sensitive topic but to compliment these rich learning opportunities. While the guide may not address everything around this area of care, if it encourages carers to talk together; and encourages carers to actively listen to individuals who have a learning disability and their families; and supports carers to try and include individuals in their end-of-life care and treatment, then it will have served its purpose. If we can get end-of-life care services right for people with a learning disability, then we get it right for anyone else accessing such services.



Chapter 1

Introduction

One of the unavoidable features of life is death. Regardless of age, wealth, status, social class or disability everyone at some point will be confronted with their own mortality and the mortality of those closest to them. The provision of care for people with a non-curable condition in today's society has until recently been described as end-of-life care and support (Costello, 2004), which is now seen to embrace a broad range of conditions such as malignant (as in cancer) and non-malignant disease (for example chronic obstructive pulmonary disease; multiple sclerosis; and motor neurone disease).

In July 2008, the Department of Health introduced the End of Life Care Strategy (DH, 2008) which establishes a clear direction for the development of services for adults approaching the end of their lives, and the term 'end-of-life care' is now used collectively to include palliative care conditions, end-of-life care and support, and end-of-life illnesses. However, the End of Life Care Strategy also recognises that life can end suddenly (such as in the situation where a road traffic accident results in someone being admitted to an intensive care unit, and hence decisions around resuscitation and so on have to be considered) and not just conditions which are diagnosed as being life limiting, where death is anticipated over time. This guide is concerned with the end-of-life care and support of people with a learning disability, which falls within the End of Life Care Strategy generally.

End-of-life care is defined as care that 'helps all those with advanced progressive, incurable illness to live as well as possible until they die. It enables supportive and end-of-life care needs of both patient and family to be identified and met throughout the last

phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support' (National Council for Palliative Care (2006), cited in: DH, 2008: 47). Terms often associated with end-of-life care include:

- hospice care – care in a specialist place where people are treated for palliative conditions
- terminal care – recognition that the end of life is imminent, usually within 48 hours or less
- care of the dying – care provided to dying people
- palliative care – holistic care that is not preventative or curative but addresses symptoms associated with the condition. Can be specialists (those trained specifically to work with palliatively ill people) or supportive care (where carers can provide care and support but are not specifically trained to give palliative care).
- end-of-life care – care provided to dying people
- supportive care – care provided by non-specialist palliative carers (Payne, Seymour and Ingleton, 2004).

A holistic approach is seen by many professionals as the basis for all high-quality end-of-life care and support (Department of Health, 2008) and such end-of-life care should be available to all who need it regardless of personal circumstances. However, it is becoming increasingly evident that where you live; poverty, social class, gender, sexuality, age, ethnicity, religion and disability can all affect the nature and quality of end-of-life care received and certain marginalised populations are likely to be 'disadvantaged dying' (Oliviere and Monroe, 2004).

People with a learning disability

People with a learning disability find it harder than others to learn, understand and communicate. People with profound and multiple learning disabilities need full-time help with every aspect of their lives – including eating, drinking, washing, dressing and toileting.

A learning disability is caused by the way the brain develops. There are many different types and most develop before a baby is born, during birth or because of a serious illness in early childhood. A learning disability is lifelong and usually has a significant impact on a person's life.

The Department of Health describes people with a learning disability as 'having a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood and with a lasting effect on development' (DH, 2001).

There are 1.5 million people with a learning disability in the UK. Like all of us, they are individuals who want different things in life and can make choices about how they want to live. They just need the right support.

However, they still remain one of the most marginalised groups in contemporary society (DH, 2001), and never more so when it comes to death and dying. "We know that many people with a learning disability have poorer health than other people and are more likely to die younger" Mencap, 2007) and end-of-life care for this population remains inconsistent across the UK.

“Ward staff do not always recognise the palliative care needs of patients with a learning disability. Therefore referrals may not be made or be made later than they would be for the general population.”

Health facilitator

This best practice guide has been written and designed as a direct result of working alongside individuals with a learning disability, families, friends, advocacy groups and various professionals in North Staffordshire during a little over two years (2006-2009). It has been developed specifically for those carers who support people with a learning disability diagnosed with a condition requiring end-of-life care from within a variety of caring contexts. The aims of this guide are to:

- raise the profile of the support needed by people with a learning disability who are dying
- acknowledge the varied impact that both dying and death may generate on individuals and family members
- promote understanding about the theoretical concepts around life limiting illness and death
- focus upon the practical approaches that may be used to support people with a learning disability diagnosed with a life limiting condition
- promote a consistency of end-of-life care and support to all people with a learning disability regardless of where they live in North Staffordshire and beyond
- act as an evidence-based resource to facilitate good end-of-life care and support to people with a learning disability.

Background to the project

In March 2001, the government issued the Valuing People white paper setting out their strategic vision for the lives of all people with a learning disability. The report recognised that while people with a learning disability can lead full and rewarding lives, many find themselves pushed to the margins of our society. The white paper (DoH, 2001) sets out the government's commitment to improving the life chances of people with a learning disability. Importantly, Valuing People recognises that merely drawing attention to the plight of people with a learning disability does not, of itself, solve problems.

People with a learning disability are recognised as being one of the most socially excluded groups in Britain today (DoH, 2001). There is widespread agreement that they have poorer health than the general population and face particular barriers when they come to be in need of end-of-life care. Often, due to communication problems, neither they nor their personal and professional carers become aware that the person with a learning disability has entered into a phase where they require end-of-life care. Those people with a learning disability that are identified as having a palliative need then face being treated by professionals who, while being trained in end-of-life care, may have little understanding of learning disability and consequently lower confidence in working effectively with them.

Since 1998 the National Network for the Palliative Care of People with a Learning Disability (NNPCPLD) has recorded a number of cases where people with a

learning disability have not received adequate end-of-life care. Reasons for such difficulties in access include informed consent issues; communication challenges; the interpretation of behaviour and how to raise sensitive issues with the people around the person with the life limiting condition.

In response to these issues, in December 2006 Royal Mencap Society launched the North Staffordshire Palliative Care Project (NSPCP). This was a two-year collaborative partnership with Keele University, funded by the Big Lottery. The project rationale clearly identified the end-of-life care needs of people with a learning disability specifically in North Staffordshire, developed, tested and evaluated principles of best practice for end-of-life care; and ultimately produced this best practice guide for the provision of end-of-life care to people with a learning disability. This guide is the first of its kind, is evidence based, and provides a template for service developers, service providers and health and social care workers in this diverse area of care.

The co-ordinator of the project acted as a conduit between generic end-of-life care services and specialist end-of-life care and support for people with a learning disability in North Staffordshire for the duration of the project. This involved the production, implementation and dissemination of information as well as the formal and informal training for professionals, carers, families and people with a learning disability to ensure their end-of-life care needs were recognised and met.

The project provided practical, emotional and information support. The project worked alongside various appropriate clinical practitioners to ensure all end-of-life care needs were met wherever

possible. This included working closely with such professionals as hospital staff, doctors, hospice staff, clinical nurse specialists, district nurses, community nurses, social workers, advocates, other charities and learning disability nurses. However the project did not involve direct clinical involvement such as pain and symptom control, or clinical interventions.

Central to the project was the development of an active case load held by the project co-ordinator, who worked with a range of individuals who were dying; individuals whose relatives were dying; associated carers; professionals; voluntary organisations; medical practitioners in a variety of settings. These experiences have informed the content of this best practice guide and examples of this work have been integrated throughout to ensure a dynamic and practice-based resource.

During the life of this short project 25 people with a learning disability have been supported (sometimes including family members and/or paid carers/ friends) with a variety of life-limiting conditions including varied cancers (13); Juvenile Huntington's disease (one person); dementia (seven people); pulmonary hypertension (one person); CHARGE association (one person); one person with heart failure; and one with renal failure. The project also involved working with ten families who had a family member diagnosed with a life-limiting condition, who also had a relative with a learning disability. Clearly people with a learning disability are as prone to the full range of ill-health conditions as the rest of the population, including malignant and non-malignant, life-limiting conditions – cancer was the main reason for referral to this project.

Over the two years, the project raised awareness of the end-of-life care needs of people with a learning disability through campaigning and advocacy activities that has promoted best practice, has shaped service delivery and supported that the rights of people with a learning disability are recognised and appropriately addressed. It should also inform and influence future policy and service development at a strategic and

operational level. The project established and facilitated an active network of relevant and interested parties. It also promoted partnership working and co-operation between agencies, both at a policy level nationally and at a practical level more specifically within North Staffordshire. As part of this project, several methods were used to ascertain views, ideas and to evaluate the work undertaken.

Table 1: Methods of information collection

Method	Rationale
<p>Active case load</p>	<ul style="list-style-type: none"> • Experiences of end-of-life care • Opportunity to reflect on issues • Work with other professionals • Network
<p>Case studies</p>	<ul style="list-style-type: none"> • Rich illustrations of the complexities of care • Overview of the nature of the work • Highlight challenges • Clarify illness and trajectories • Identify interventions used
<p>Focus groups <i>Multi-professionals, family carers, people with a learning disability throughout the project</i></p>	<ul style="list-style-type: none"> • Multidisciplinary perception of current provision • Views and perception of adults with a learning disability
<p>Evaluation forms</p>	<ul style="list-style-type: none"> • To identify professional experiences across England • Identify training and resources (gaps and current provision) • Highlight positive practice initiatives
<p>Referral sheets</p>	<ul style="list-style-type: none"> • Demographic information (numbers, ages, gender, faiths, ethnicity, etc.) • Contextual information • Type of disease

Gathering information

During the project, several approaches were introduced to collect information about the nature of the ill-health experienced including the impact of the illness on people with a learning disability and their families; and the difficulties that professionals had in offering meaningful support. Tools were also used to identify perceived gaps in local and national end-of-life care provision. Five methods were used at various stages throughout the project, all of which were introduced to primarily inform the best practice guide, an overview of these approaches are presented in Table 1.

All this information has been used to support the development of this best practice guide. Case examples, vignettes and the voices of people with a learning disability, carers, parents and other professionals involved with the project are used throughout (with their consent). All first names used are the actual names of people involved and are not pseudonyms, unless otherwise stated– this was the choice of those participating.

A national perspective

To gather a national perspective around this topic, around 800 survey questionnaires were distributed to professional groups involved in providing end-of-life care and support (including hospices, hospitals, district nursing services, GP practices, health facilitators, North Staffs Carers Association, social workers, educational providers and student nurses) across the United Kingdom in an effort to define professional involvement; establish familiarity with the learning disability

population; and to identify challenges to end-of-life care and support for this marginalised group.

A total of 227 questionnaires were returned and the range of geographical spread was good, receiving responses from all corners of England, and limited responses from Ireland, Scotland and Wales. Of those questionnaires returned (N=227), more than that 61.2% respondents identified that they had worked with people with a learning disability who had end-of-life care needs in the previous 12 months, around 69.1% had received no training or education on the topic of end-of-life care and learning disability. This was a key factor in developing this best practice guide.

Key points

- People with a learning disability often experience barriers to end-of-life care and support. Professionals should be aware of these barriers and try to overcome them.
- The North Staffordshire Palliative Care project was established to develop, test and evaluate principles of best practice in end-of-life care, the outcome of which was to produce this best practice guide.
- Several approaches were introduced to collect information about the nature of the ill-health experienced, including the impact of the illness on people with a learning disability and their families and the difficulties that professionals had in offering meaningful support. Tools were also used to identify perceived gaps in local and national end-of-life care provision.



Chapter 2

**Persistent challenges to accessing
end-of-life care for people with a
learning disability**

Health needs and health access

Inherent social problems (including unemployment, limited exercise and restricted social activities), poor diet and additional health problems (such as epilepsy and dementia) all serve to increase and compound the general health status of people with a learning disability as highlighted by *Treat me right!* (Mencap, 2004). The more recent *Death by indifference* report (Mencap, 2007), coined the phrase ‘institutional discrimination’ with regards to healthcare received by people with a learning disability in the National Health Service (NHS). Institutional discrimination happens when the people working in a place or organisation:

- do not value all people equally
- do not understand that different people have different needs
- do not change the way they deliver a service so that it meets different needs. (Mencap, Easy Read, 2007:6)

The *Death by indifference* report is short but powerfully poignant, and portrays the sad stories of six people with a learning disability who died unnecessarily (Mencap, 2007). Clearly people with a learning disability may challenge health services for a variety of different reasons, but until the questions raised by our recent report are addressed, such challenges will ultimately never be resolved.

The resultant independent enquiry into access to healthcare for people with learning disabilities (‘Healthcare for all’, Sir Jonathan Michael, 2008) is a comprehensive response. It

recognises that the findings of the *Death by indifference* report were not isolated cases and acknowledges the inherent challenges involved. Michael (2008) makes ten recommendations for improving healthcare for this population, integral strands of these recommendations being the themes of leadership, visibility and assurance. Partnership working, and user and carer involvement remain key to effective support and future service development, to address the sense of ‘invisibility’ that individuals and parents often feel, particularly in a healthcare context. Ultimately healthcare workers, managers and services have responsibility for all patients receiving healthcare, regardless of whether they have a disability or not.

Of the six cases reported in the Mencap report (2007) only one involved cancer, but the many issues surrounding the provision of end-of-life care for people with a learning disability are well reflected within the literature. It is estimated that cancer accounts for up to 16% of deaths in people with a learning disability (Hollins et al, 1998; Patja, 2001) and therefore cancer and other palliative, non-malignant conditions are important in the overall general healthcare of this population.

Macmillan (2003) identified four key barriers that restrict access to cancer care services: physical, professional, emotional and social, cultural or religious/spiritual. For people with a learning disability, specific knowledge and attitudinal beliefs around the learning disability itself are also important features that may impinge access (Figure 1).

Figure 1: Barriers to accessing end-of-life care services (after Macmillan Cancer Support, 2003)



People with a learning disability are often lost behind such barriers that compound to make access to end-of-life care and support difficult. Such barriers may indeed be compounded if you are an older person with a learning disability (Jenkins, 2005) experiencing, for example, dementia (Frey, 2006). People with a learning disability are a vulnerable population generally, but particularly so when it comes to loss, dying, death and bereavement (Read and Elliott, 2003), and remain reliant on so many people for so much. They are often actively excluded from death and dying, and the more complex their needs (for example, if the person has a communication impairment and/or challenging behaviour), the greater the likelihood of this deliberate exclusion (Read and Elliott, 2003). A common feature among people with a learning disability is communication difficulties.

Communication

Some people with a learning disability are very articulate and can communicate thoughts and feelings in a very profound

and meaningful way. However, other people may struggle to communicate without the use of communication tools or alternative communication systems. One of the biggest obstacles to accurate medical assessment is communication (Tuffrey-Wijne, 2003) and difficulties in accessing appropriate assessment and treatment often results in poor outcomes. For many people with a learning disability this results in a late diagnosis with poor prognosis and early death (Tuffrey-Wijne, 1997). Communication is not simply about the ability of the person with a learning disability to communicate to another person, it's the ability of the other person to interpret, respond and ensure the response has been heard and understood that is also important. Such reciprocal communication is fundamental to any end-of-life care and support. It is estimated that more than 50% of people with a learning disability have some form of communication impairment (Kerr et al, 1996). According to Ambalu (1997), such communication impairments may be found in cognition, hearing, language, speech, or social interaction.

Specific issues surrounding reciprocal communication in the end-of-life care context include the person's ability to express emotions verbally or otherwise; the carer's ability to identify, address and effectively overcome any barriers to effective communication; difficulties in communicating about abstract concepts such as illness, cancer or death with the person who is dying; and giving bad news (Read, 1998). Such communication difficulties may affect how the person indicates their discomfort or distress (Keenan and McIntosh, 2000).

Communication: symptom recognition

Symptom recognition and identification may be difficult with this population as a result of communication impairment and diagnostic overshadowing (Brown et al, 2003), where the label of learning disability overshadows all potential for the recognition of other serious ill health symptoms.

Diagnostic overshadowing describes the tendency of the professional to overlook symptoms of ill health and to attribute them to being part of 'having a learning disability'. For example, carers' fears regarding an elderly woman taken to her GP because of general apathy, refusing to eat and weight loss were dismissed, since the GP explained that this was part of her having Down's syndrome. The carers persisted, and eventually the woman was diagnosed with lung cancer. Pain and symptom management may be fraught with reciprocal problems, as the individual with a learning disability struggles to indicate worsening symptoms and carers struggle to

understand when to offer, administer or increase prescribed medication.

Some people with a learning disability may recognise their own ill health but may be afraid of doing something about it (as is frequent in the rest of the population) or harbour a fear for hospitals and what they might bring (Tuffrey-Wijne and Davies, 2006).

Communication: assessment

Assessment of pain of people with a learning disability generally is often difficult due to idiosyncratic reactions, vague descriptions and is compounded by communication issues, and the professional carer may be wholly reliant upon familiar carers (Foley and McCutcheon, 2004). The usual pain tools may be inappropriate for many people with a learning disability. The DisDat tool (Regnard et al, 2003) is a tool that is a functional assessment of distress that is based upon behaviour observations as opposed to verbal descriptors of pain and other associated symptoms, developed specifically for people with a learning disability, and can be found on the following website: www.cfr.ac.uk/disdat/disdattools.html

A professional carer's perspective

A lack of knowledge and professional experience (Thornton, 1996; Lindop and Read, 2000; Read, 2006) may contribute to create negative attitudes towards patients with a learning disability (Read 2005), which may manifest in professional ambivalence and discrimination (Mencap,

2004). Ultimately this may result in ‘institutional discrimination’ towards people with a learning disability and resulting in poor healthcare (Mencap, 2007).

“It’s lonely when you are a professional among other professionals...”

Learning disability nurse

Indeed, even carers who work with people with a learning disability (and the services and organisations within which they work) may not be fully prepared for the death of the people they care for (Todd and Blackman, 2005; Todd, 2006). Yet such carers can perceive the experience as being very positive if enabled to access appropriate professional and personal support (Brown et al, 2003).

Carers remain committed to providing good quality care and support during this time, despite not having all the appropriate knowledge and skills to provide end-of-life care to their personal satisfaction (Todd, 2004). Many learning disability carers face ‘role blurring’, as they move seamlessly (if possible) between performing skilled interventions around complex needs (e.g. physical care); simultaneously acting as pseudo families (Brown et al, 2003); while also supporting other family members and friends who

have a learning disability who live in a care home, as the person approaches death.

Many learning disability carers (or indeed family carers) may not be familiar with the concept of end-of-life care, but have had to learn quickly in order to support the people they care for. Similarly, many palliative care workers remain unfamiliar with people with a learning disability, but have had to adapt quickly in order to offer the care and support that is vital at the end of life. Subsequently, collaborative working is the key. Carers who work with people with a learning disability need to work with people who have end-of-life and palliative care expertise in order to provide appropriate, high quality end-of-life care for this population. If professionals cannot work effectively together, then people with a learning disability will die alone, both actually and metaphorically.

People with a learning disability have more similarities to the rest of the population than differences from them (Read, 2005) yet some professionals tend to highlight and focus upon the differences. These, in effect, become barriers to effective access and ultimately effective end-of-life care. Collaborative working, and multidisciplinary training and education, may help to demystify these differences. Similarly, having a planned approach to end-of-life care for this population regarding malignant and non-malignant diseases may be the way forward (Read and Elliott, 2006).

Disenfranchised dying

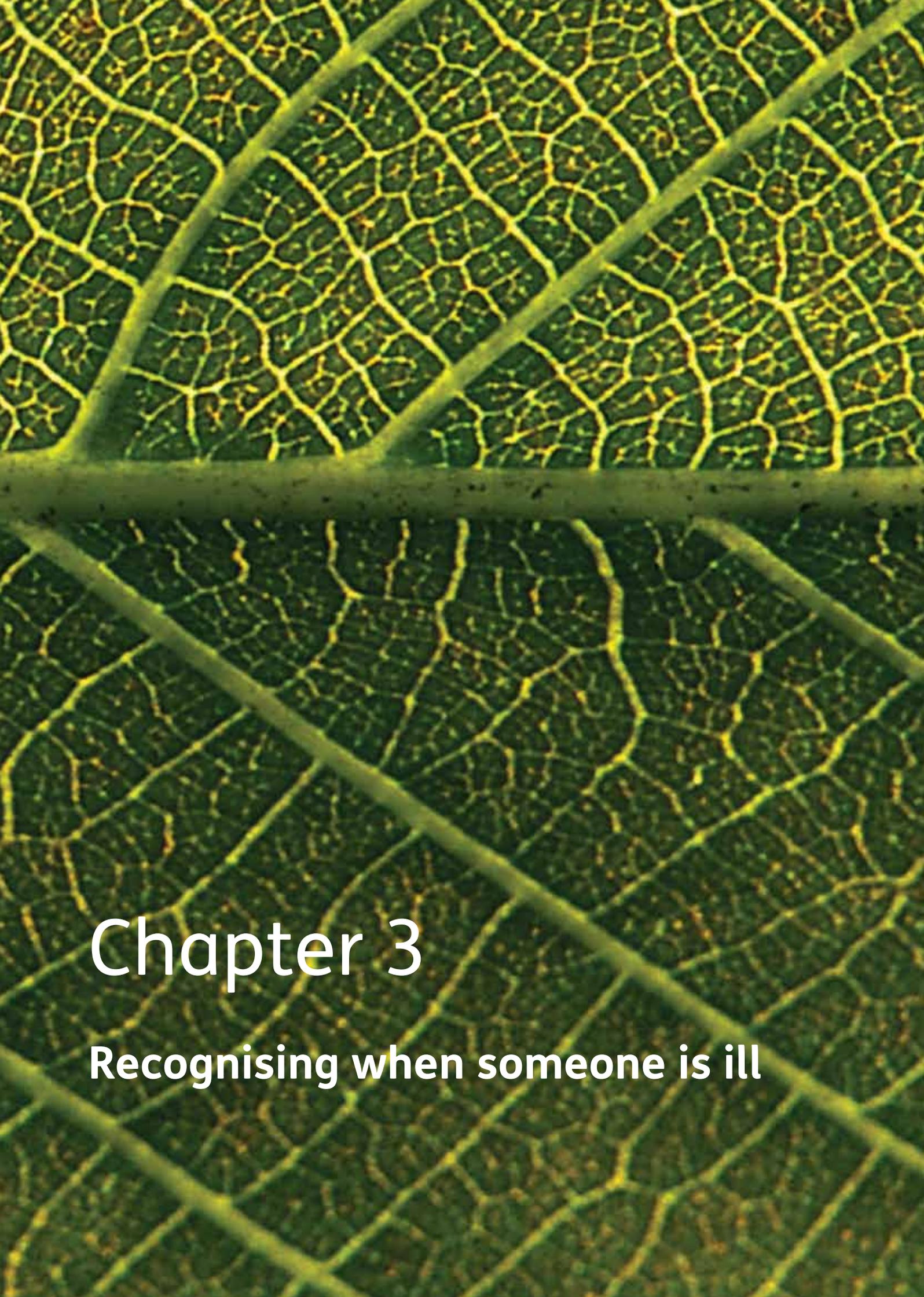
The timing of some deaths may be anticipated to some degree, as with some cancers for example. But for the person with a learning disability most

deaths are actually sudden deaths (O’Nians, 1993), since carers may be reluctant to tell (and thus prepare) the person that someone close to them (or indeed the person themselves) is facing imminent death. This may be due to a lack of knowledge and skill on the carer’s part, or a lack of confidence or insight. It could also be perceived as over-protection, where carers try to protect the person from the raw reality of what is happening to (or around) them. This can ultimately exclude the person from being involved in the last days of life of their loved ones (or their own life), thus prohibiting meaningful goodbyes and increasing the potential for difficult bereavement responses afterwards. Such experiences have been identified as disenfranchised death (Read, 2006).

When death is not openly acknowledged with the dying person, and where the dying person is socially excluded from the process of dying and deliberately excluded from the decision-making process surrounding the terminal illness, it is described as disenfranchised death (Read, 2006). Carers need to remain mindful of this and its subsequent effects.

Key points

- People with a learning disability may challenge health services for a variety of different reasons.
- Communication is the key to effective end-of-life care and support.
- People with a learning disability have more similarities to the rest of our society than differences from them. However, some professionals tend to highlight and focus upon the differences.



Chapter 3

Recognising when someone is ill

Signs and symptoms to look out for

Some people in the general population may not recognise initial symptoms or changes in their body that indicate ill-health and disease. Some people may have had bad experiences of hospitals, doctors and nurses and have a reluctance to follow up any noticeable symptoms. And some may be too afraid to follow up changes that are recognised in case it leads to a poor diagnosis. People with a learning disability may be no different.

Alan had lung cancer, and was afraid of getting ill, of being ill, accessing services; seeing the doctor, and of his illness getting worse. He was more scared of going in to hospital than dying at home. Similarly, John Davies (Tuffrey-Wijne, 2007) knew that he was ill (he had penile cancer) but had ignored his illness for many months. He urges everyone to go to the doctor as soon as the person notices something out of the ordinary because 'life is precious' (Tuffrey-Wijne, 2007). People with a learning disability may not easily recognise changes in their bodies that are a sign of illness. Some people may lack the communication ability to voice any concerns they have. Some people may not actively look for signs or body changes. Things to look out for are found below:

- swellings or lumps
- clothes not fitting properly due to changes in body shape
- weight loss or gain
- personality changes
- changes in eating habits
- changes in toilet habits
- generally feeling unwell

- tiredness or lethargy
- changes in behaviour
- asking for pain relief more often than usual.

All carers need to remain alert to spotting and exploring any changes in the health of the person with a learning disability. Carers could become more proactive by encouraging people to look for changes in their body – by using clear words and pictures in resource books (e.g. Donaghey et al, 2002) – to help people become more aware of the need to attend health and wellbeing clinics, classes and groups.

One example of good practice in this area is the breast awareness project in Buckinghamshire, where a checklist was devised to enable accurate recording of monthly observations, and a resource pack was developed which featured pictures of breast conditions (for both men and women), guidelines for completing the checklist and local resources (Symonds and Howsam, 2004).

Such work is happening across the country, sometimes led by health facilitators, but there are few examples that are published and thus can be easily replicated. In North Staffordshire, a multidisciplinary group have developed a series of leaflets to support people with a learning disability at the end of their lives. These include four leaflets for people with a learning disability in pictorial format; a 12-page booklet for personal carers, and a 20-page booklet for professional carers. These resources are available from s.c.read@nur.keele.ac.uk

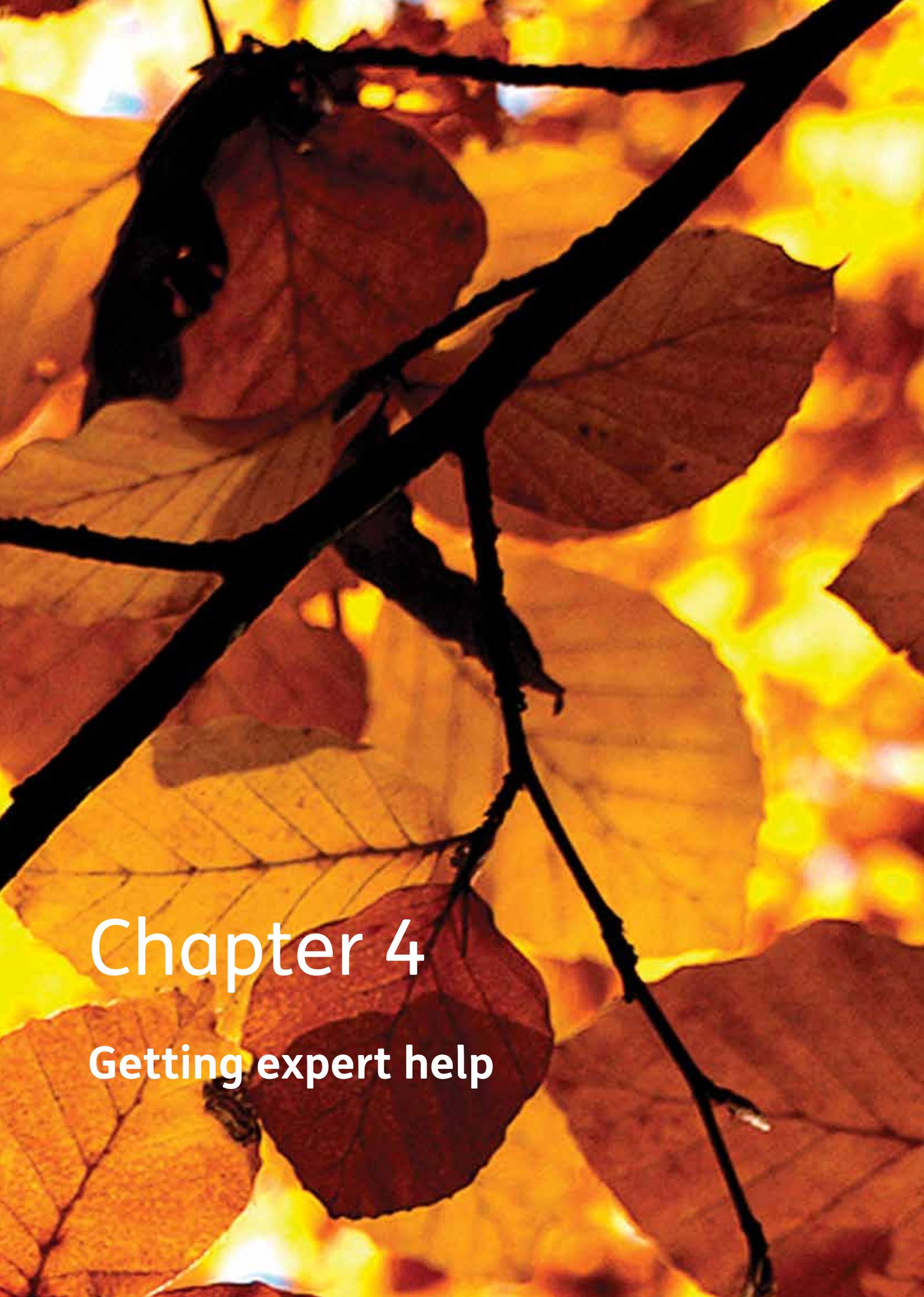
Getting expert help

As soon as there is a suspicion of any health change, the first port of call is the person's general practitioner (GP). Accessing the GP may take time and planning, as the person may require a double appointment (to allow time for effective communication between patient/GP/carer); the person may need to be accompanied by a familiar carer who knows about that person and can advocate for further investigations if deemed appropriate. The carer can also support the GP in communicating with the person, and offer supplementary information, if appropriate.

Some professionals may see the learning disability as an excuse for other presenting health needs (for example a person's increase in self-injurious behaviour could be as a result of needing a medication review rather than investigations for potential ill health) and as such may be reluctant to investigate further health needs. Such diagnostic overshadowing is common – all professionals need to remain mindful of this and need to prioritise the person's health needs rather than solely focusing upon the disability label. Planning for all health-related appointments and admissions for diagnostic procedures and tests is important, and requires time and creativity for successful outcomes (Jackson and Read, 2008).

Key points

- All carers need to remain alert to spotting and exploring any changes in the health of the person with a learning disability.
- Carers could become more proactive by encouraging people to look for changes in their body by using clear words and pictures.
- Preparing the patient for diagnostic procedures and tests is important, and requires time and creativity for successful outcomes.



Chapter 4

Getting expert help

Diagnosis and prognosis

A diagnosis of any condition is important for effective and appropriate treatment. A diagnosis will be made following a series of investigations or tests usually at the general hospital or specialist cancer hospital or units. Communication is crucial to effective medical assessment (Tuffrey-Wijne, 2003) and assessment is part of the diagnostic process. Not being able to communicate well might affect this process, and familiar carers will be useful to work alongside other professionals and medical people to help with this.

Having a learning disability might be seen to mask symptoms of ill health, additionally the person cannot or does not recognise changing health status. Also some professionals may not see the symptoms as being obvious but as part of the disability itself, where the disability is seen to overshadow presenting symptoms, which we have mentioned several times previously in this guide as diagnostic overshadowing. In the past this has led to severe ill health being overlooked, leading to late diagnosis and poor prognosis (Tuffrey-Wijne, 2003). Personal carers need to be watchful about any change in health and to record such changes and refer for medical advice when unsure.

Communication may be difficult across (and within) professional groups and may result in professionals working in isolation with true holistic care failing to be provided. Collaborative working is the key (as always) to effective support, and never more so than when supporting a person with a learning disability with end-of-life care needs.

“...my grandma’s died and she, when my grandma died, she died of cancer and she was in pain all the time.”

Young woman with a learning disability

Pre-planning for diagnostic procedures and health tests remains important, requires time and creativity for successful outcomes (Jackson and Read, 2008). Carers of people with a learning disability need to be proactive in thinking ahead about what might help the person to understand what is going to happen. Photographs and planned visits to the hospital in preparation for the appointment might take time, but will ultimately save time and help to minimise distress with such appointments. Similarly, medical and other health professionals (for example, radiologists) may need help from carers of people with a learning disability to understand and fully appreciate the difficulties that the individual might be facing because of the nature of their disability and how this may be overcome. It is also important that staff in learning disability services come to understand what to them may be unfamiliar diagnostic procedures. Hence two-way learning is a positive way forward for all those involved.

Once a diagnosis is made, telling the person who is ill becomes an important part of their journey, as decisions around treatment options, preferred priorities for care, and even preferred place of death, may have to be considered by all those involved but focused around the wishes of the patient.

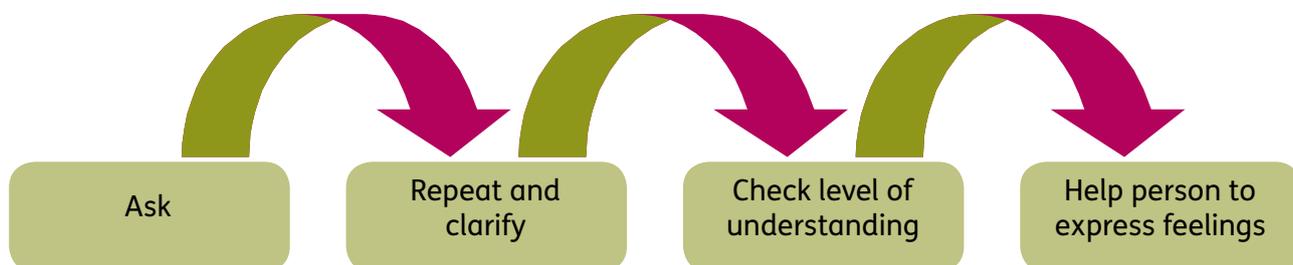
When the news isn't good

“I asked the doctor ‘Can you tell me, what’s wrong with me please?’”

Man with a learning disability, diagnosed with cancer

Being told that you (or someone you care about) have a life-limiting condition may come as a shock, and is often difficult to understand and accept initially. According to Buckman (1984) bad news is anything that drastically and negatively alters the person’s perception of the future, and the very nature of bad news means that it is often something that is not welcomed. Medical professionals may use Buckman’s Six Step Protocol (1991) – this is a useful framework that supports professionals to develop a therapeutic dialogue around delivering difficult news. It was further developed for the general population and following its usage, carers might need to use the ARCH model (Read, 2006) – this was developed specifically for breaking difficult news to people with a learning disability.

Figure 2: The ARCH model – a framework for breaking bad news



Ask: Find out what the person already knows. Always use the person's name. Use straightforward questions to find out information. Ask what the person wants to know.

Repeat and clarify: Be prepared to go over information time and time again, in different ways (using books, photographs etc.) and simplify if necessary. Carefully listen to the person and be guided by what they want and need.

Check level of understanding: Explore how much they know about the illness and what it means to them. Go back to previous stages if necessary. Be guided by the person.

Help the person to express feelings: Encourage expression of feelings, listen carefully and give support. Help the person to describe feelings, and explore what help they feel they might need next, future support options and choices and letting other people know (such as the day centre) if necessary (after Read, 2006).

The ARCH model may help the carer to identify what the person has understood (or not) about the illness, and enables the carer to clarify, explore and explain what they have been told and what might happen next. While medical professionals may have some awareness about disease progression, they may not be able to give an accurate prognosis in terms of precisely how long the lifespan of an individual may last. This is because factors such as the nature of the illness, when the diagnosis was made, how early (or late) the illness was identified, what treatment has been given, how the person reacted to the treatment, the impact of the treatment on the disease, might all affect prognosis. Breaking difficult news is never

easy, and carers must be careful not give unrealistic expectations to the person.

“We don’t talk about it {dying} much but we do think about it...”

Man with a learning disability

Supporting someone with a life-limiting illness is not easy, and carers may need additional support at this sensitive time. Clinical supervision and peer support are useful resources to support individuals throughout the illness and as death approaches. Once a diagnosis has been made, and a decision to provide end-of-life care has been taken, help, care and support can be found from a variety of different people and accessed in various, different places.

“It’s a really lonely place when you are caring for someone that’s ill and needing palliative care...”

Learning disability nurse

End-of-life care and support can be delivered by many different people: those providing day-to-day care to patients and carers in their homes and in hospitals and palliative care specialists who provide end-of-life care (consultants in palliative medicine and clinical nurse specialists). Those providing day-to-day care should be able to:

- assess the care needs of each patient and their families across the domains of physical, psychological, social, spiritual and information needs
- meet those needs within the limits of their knowledge, skills, competence in palliative care
- and know when to seek advice from or refer to specialist palliative care services.

Specialist palliative care services are provided by specialist multidisciplinary end-of-life care teams and include:

assessment, advice and care for patients and families in all care settings, including hospitals and care homes; specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams; intensive co-ordinated home support for patients with complex needs who wish to stay at home (NAPC).

www.ncpc.org.uk/download/PalliativeCareExplained.doc

Specialist care and support for end-of-life care can be accessed by all of the population but people with a learning disability have access to additional support because of their individual needs. An overview of such support is provided in table 2, but it is worth remembering that certain professionals (for example, physiotherapists) may offer both general and specialist palliative care and support. This list is not exhaustive.

Table 2: People who might help and places where help is provided

End-of-life care and support	Where accessed	Specialist end-of-life care	Where accessed
Friends and family	Home	Hospice at home staff	Home
Chaplains	Home, place of worship	Chaplains	Home, place of worship
GP practice	Surgery	Occupational therapists	Hospital, hospice, home
District nurses	Home	Physiotherapists	Hospital, hospice, home
Nurses	Home, hospital	Social workers	Hospital, hospice, home
Physiotherapists	Home, hospital, hospice	Consultants/ doctors	Hospital, hospice
Community learning disability nurses	Home	Nurses	Hospital, hospice, home
Support workers	Home	Cancer/palliative care nurse specialists	Hospital, hospice, home
Learning disability nurses	Home	Home	Hospital, hospice
Day care staff	Day centre	Home	Hospital, hospice, home
Carer support groups	Meeting rooms	Home	Hospital, hospice, home
Complementary therapists	Home, hospice, hospital	Home	Home, hospice, hospital
Health facilitators	Home, hospital	Home	Hospital, hospice, home
Advocates	Home, hospice, hospital	Home	Hospital
Social workers	Home, hospice, hospital		

Circle of support

Counselling as support in the general end-of-life care context is usually sought from personal carers who may not be trained counsellors (Parkes et al 1996), but who may use counselling skills such as actively listening and 'being there' for the person. Consequently, people with a learning disability who are diagnosed with a life-limiting condition are likely to access support from familiar carers. Therefore carers need to be prepared for, and supported with, this role (Read, 2006). People who care about a person often end up caring for them and being there for the person. Sharing emotional pain and hearing and sharing the tears are all part of the support process.

As death approaches, the dying person may want to try and make sense of life, and for some this might be a time of celebration or regret, or a combination of the two. Carers should make time to be with the dying person and help them to make peace with those around them. It may be a time to reflect on past experiences, and a time to help the person to 'close the circle of friendships' (O'Kelly and O'Kelly, 2006), which are illustrated in figure 2 below.

Figure 2: Closing the circle of friendships



This means helping the dying person to say appropriate and meaningful goodbyes to those closest to them. All people involved in a person's life will need variable support both when the person dies and afterwards. Carers should try to keep friends (including other people with a learning disability) informed and involved in what's happening, and encourage individuals to say their goodbyes. This might help the bereaved in accommodating their loss in the months and indeed years to come. You might also require the support of a professional counsellor (attached to the hospice or other professional service) to keep yourself emotionally safe and well.

Care pathways

Person-centred planning (PCP) is an integral part of the care planning process (DoH, 2001), and refers to a set of values or a philosophy that holds the individual at the centre of the care received (Matousova-Done and Gates, 2006). Such care-planning approaches have been developed to address specific areas of care such as community, forensic and mental health settings, and in response to complex needs, promoting health and end-of-life care settings (Gates, 2006). PCP fits well within end-of-life care, and such approaches have been related explicitly into the end-of-life care context care to address the complexities of the duality of these conditions (Read and Elliott, 2007).

In recent years, end-of-life care has become a focus for the Department of Health who have endorsed specific tools developed to improve end-of-life care

within a variety of settings, including the Liverpool Care Pathway (LCP), the Gold Standards Framework (GSF) and the Preferred Priorities for Care (previously Preferred Place of Care) (Higginson, 2003). The LCP was developed by Dr John Ellershaw, medical director, Marie Curie Hospice, Liverpool, to transfer the hospice model of care into other settings, i.e. hospital, nursing homes and the community. It is a multi-professional document which provides an evidence-based framework for end-of-life care – the framework is now being trailed and integrated into other care contexts such as cardio-thoracic and intensive-care settings.

The GSF was developed by Dr Keri Thomas, GP Walsall, and is a practice-based system to improve the organisation of care for patients within the last six to 12 months of life. It identifies several key standards relating to key aspects:

- co-ordination of care
- control of symptoms
- continuity of care
- continued learning
- carer support
- care of the dying.

The pathway provides guidance on all aspects of care in the last 48 to 72 hours of life, including comfort measures, anticipatory prescribing of medicines, discontinuation of inappropriate interventions, psychological and spiritual care, and family support.

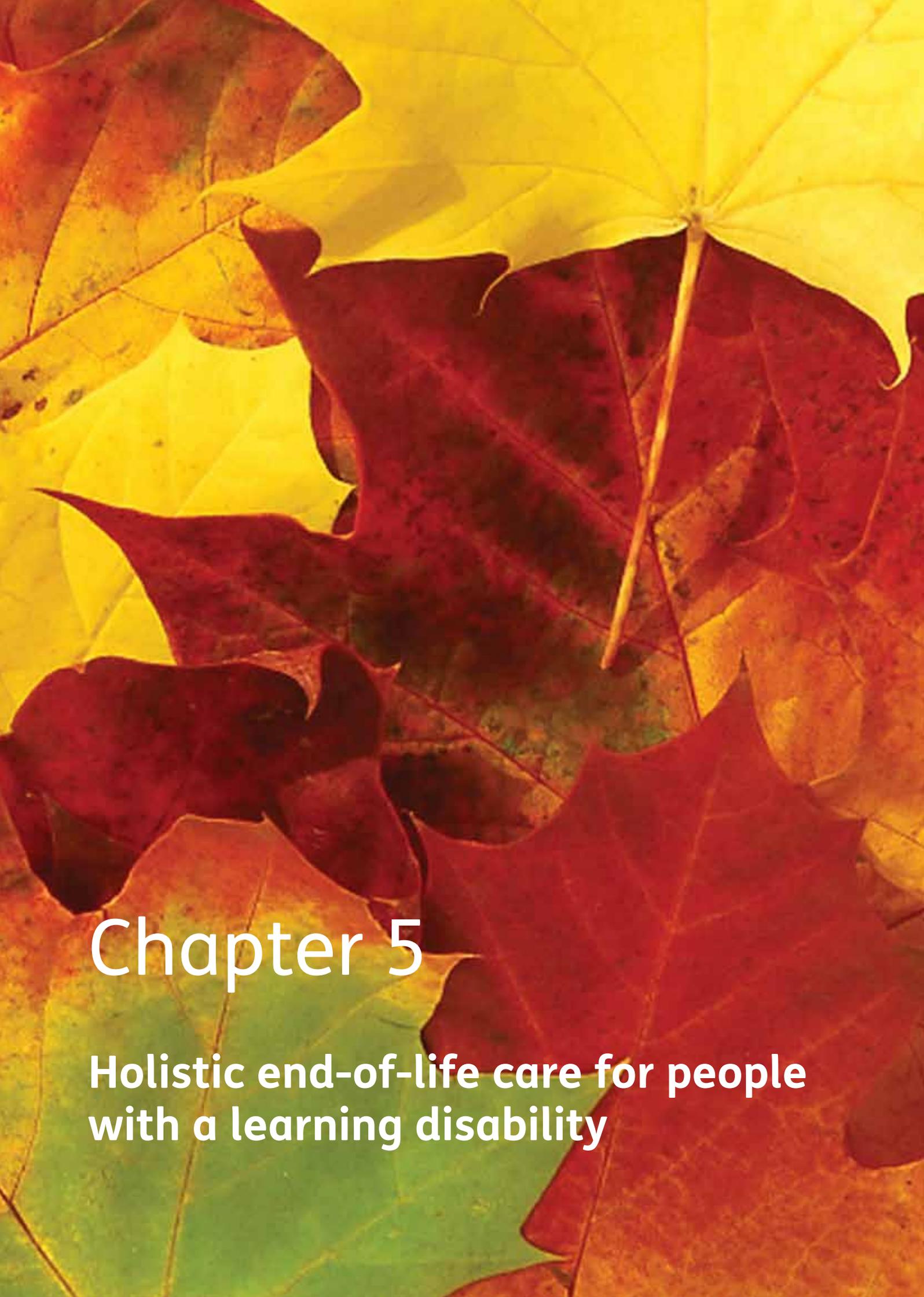
The Preferred Priorities for Care (previously known as Preferred Place of Care) is a document that originated in the Lancashire and South Cumbria Cancer Network as part of a district nurse

education programme. This document reflects the importance of discussing with the individual any personal priorities, preferences or wishes regarding treatment at the end of life.

These tools all act as a guide to healthcare professionals to ensure that patients with life-limiting conditions can be offered choices regarding their care in the last year of life and in the terminal phase of their condition (i.e. the last few days of life). People with a learning disability challenge all healthcare professionals involved in the application of these frameworks, since these tools are most effective when reciprocal communication is at its best. Therefore the successful application of such tools with people with a learning disability will be dependent on collaborative approaches across inter-disciplinary teams to maximise communication and to meet individual priorities and choices of the individuals involved (Read et al 2008).

Key points

- A diagnosis of any condition is important for effective and appropriate treatment.
- All people involved in a person's life will need variable support both when the person dies and afterwards.
- Breaking difficult news should be done by familiar carers – they must be guided by the person receiving the news and carers should avoid creating unrealistic expectations.



Chapter 5

**Holistic end-of-life care for people
with a learning disability**

Holistic care

Holistic care is central to the delivery of quality end-of-life care and support, regardless of disability, race, culture or creed. Ultimately the person who is facing a life-limiting condition should be the focus of any care, treatment and support offered. Holistic care incorporates the physical, psycho-social, emotional and spiritual dimensions of a person. It also includes support for families and friends of the ill person. True holistic assessment is often difficult, due to:

- the progressive nature of the illness (and any associated declining functions, such as communication)
- the social context (including the family and its dynamics)
- the limitations of the tools available to make any assessment
- where the assessments take place and who conducts them
- a lack of concrete understanding of complex terms (such as spirituality).

However, experienced practitioners often have a wealth of understanding about the tools available, make assessments over time (to allow for changes) and have the care and perseverance to do the best they can for each individual.

Holistic care for people with a learning disability

Holistic care is not a new concept to caring for people with a learning disability and remains an integral part of the care-planning process (DoH, 2001). Therefore professional carers should be aware of the nature of holistic care, but not from

a dying perspective specifically. Most learning disability carers tend to focus on helping the person to live with a disability rather than dying with it – this raises issues when the person is diagnosed with a life-limiting condition. Therefore, the challenge is to merge holistic care from both a learning disability and end-of-life care perspective, drawing on the expertise of professionals from each field.

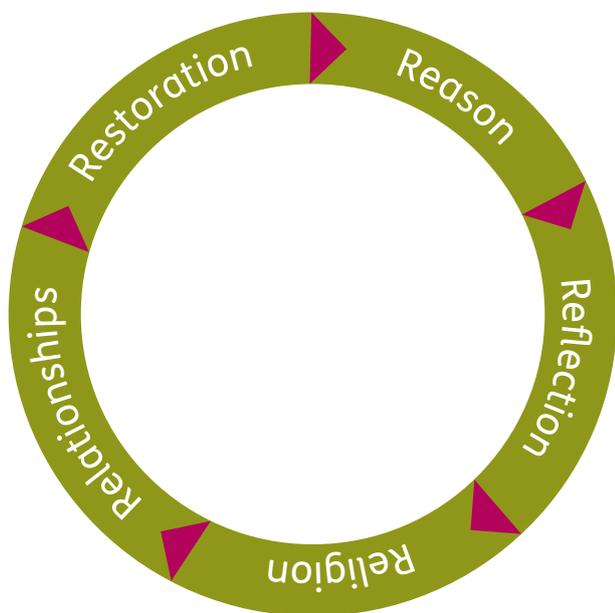
Facilitating holistic care

Finding ways of effectively communicating with the person with a learning disability in the end-of-life care context remains challenging when trying to provide holistic care. Carers need to be creative, using clear words and pictures and mediums such as picture boards, life-story work (Read and Bowler, 2007), photographs, videos, music and artwork in order to assess the person's needs. Talking to family and friends and working with familiar carers provides a clearer picture of the person and promotes holistic care.

Generic assessment tools may be adapted to suit the needs of the person with a learning disability, and specific assessment tools (such as the DisDat, Reynard et al, 2003) may be appropriate for some people, since managing pain and distress is important to all people, as no-one wants to die in pain. The ability to assess the physical symptoms of a person with a learning disability requires sensitivity to the individual concerned and an overt symptom-management intention, which can only be achieved by good collaborative working forged on the development of relationships with those who know the person well (Reynard et al, 2002).

‘Spirituality is a significant presence in people’s lives, and by extension will be a significant presence in how they die too,’ Swinton (2006:121). Spirituality has been defined simplistically as the need of the whole person to be themselves (Vanier, 1973), and as such incorporates everything about the person. Govier (2000) provides a useful foundation for the assessment of spiritual needs by using the five R’s:

Figure 3. The five ‘R’s of spirituality (Govier, 2000).

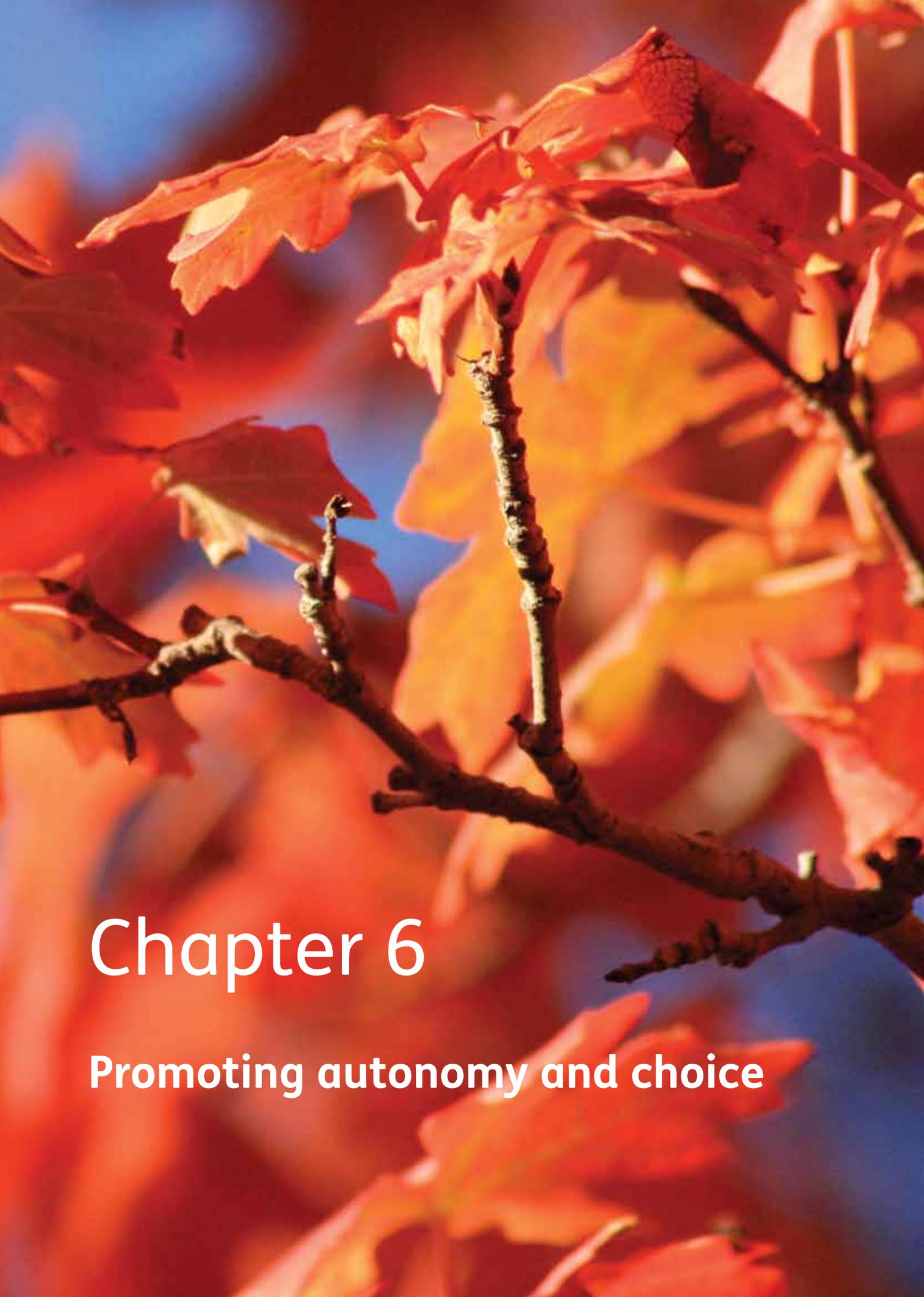


Identifying, assessing and responding to spiritual needs at the end of a person’s life is often overlooked, particularly when the person has a learning disability, but the five R’s (Govier, 2000) may provide a useful framework to consider, particularly since they incorporate areas other than religion. The skill is for the carer to have a basic understanding of the concept of spirituality, its importance in everyday life and death, and the ability to facilitate emotional expression of such issues with the person. People with a learning disability are often passive recipients of care, and may not know how (or indeed what) to ask for at times of distress.

Again, collaborative working and creative communicative approaches might be the key to unlocking the spiritual needs of this population. There are several educational packages (for example, Hatton et al, 2004; Swinton and Powerie, 2004) which help to demystify the concept of spirituality from a carer and disability perspective and many people receive support from a religious body or establishment.

Key points

- Holistic care is central to the delivery of quality end-of-life care and support, regardless of disability, race, culture or creed.
- Talking to family and friends and working with familiar carers provides a clearer picture of the person and promotes holistic care.
- Most learning disability carers tend to focus on helping the person to live with a disability rather than dying with it – this raises issues when the person is diagnosed with a life-limiting condition.



Chapter 6

Promoting autonomy and choice

Involvement (disenfranchised dying)

Some people with a learning disability die without knowing the severity of their illness, or without knowing that their family/friends are dying. In the NSPC project, a woman with Down's syndrome who had dementia was never told of the diagnosis. Her condition deteriorated very quickly and involved large lapses of unconsciousness, so she never knew that she was dying. During the NSPC project, most people with a learning disability were aware of the nature and potential extent of their illness, although one person would not accept that she was dying until a few days before her death. Denying one's impending death is not unusual. However, people with a learning disability have been described as experiencing disenfranchised death (Read, 2006) – this is defined in figure 2 in chapter 4.

Features of disenfranchised death include:

- the autonomy of the dying person is not recognised
- the person is not told or prepared for his/her pending death
- the person's 'rights to know' are overlooked, as carers struggle to communicate in a meaningful way
- cumulative challenges support disenfranchised death i.e. reciprocal communication challenges, the nature and context of death and the person's cognition (Read, 2006).

To minimise the potential for disenfranchised death, people with a learning disability must be treated with respect and dignity, and treated as an adult throughout their illness. It involves a creative way of working, in which the person is empowered to make choices and decisions about the care and treatment they may be receiving. Effective communication is, therefore, essential.

‘Disenfranchised death is death that is not openly acknowledged with the dying person, where the dying person is socially excluded from the process of dying and deliberately excluded from the decision making processes...’

(Read, 2006: 96)

Autonomy and choice

Promoting autonomy may be difficult when the person has a learning disability, because they may have a history of being passive recipients of care, reliant on so many others for so much. Often, they lack the general awareness and understanding to ask for things that aren't obviously there. Health professionals need to be mindful of this, and state things that may be possible (for example, that the person can change the appointment if it becomes inconvenient, that the person can take someone with them to the appointment, that the person can have a tape recording of the meeting with the consultant) that may seem fairly obvious to others.

Actively involving people with a learning disability throughout their treatment will undoubtedly promote their autonomy and facilitate informed choice. There are many ways to do this, including:

- having clear words and pictures in information leaflets about the services and specific treatments available
- having someone who has the time to go through information and explain complex terms in clean language
- giving people the opportunity to ask questions.

The Books Beyond Words series (St George's Hospital Medical School) include a series of texts around death, dying, cancer and bereavement that are written in plain English, and accompanied by drawings using expressive use of colour. Such books include 'Getting on with Cancer' (Donaghy et al, 2002),

'Keeping Healthy Down Below' (Hollins and Downer, 2000); 'Looking After my Breasts' (Hollins and Perez, 2000) and 'Looking after my Balls' (Hollins and Wilson, 2004), and can be used before or after diagnosis.

Everyone has the right to be actively involved in making decisions about their health and healthcare, particularly at the end of their life when decision-making has a sense of finality. Individuals also have the right not to be involved in making difficult decisions, if that is their informed choice. These decisions are reliant on accurate information being given to the person by a knowledgeable professional, in a language and format that makes it easy to understand. Unfortunately, not all healthcare professionals are aware of the importance of clear, straightforward, easy-to-understand language. Therefore, patients with a learning disability are often unaware of treatment options and available choices. This means that other people might end up making decisions on their behalf, perhaps believing that they do not understand and cannot make the decisions for themselves, or are simply not competent to do so. The DH offers guidance on consent from the following website:

www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/YourRightsInHealth/DG_10016888

Capacity and consent

The Mental Capacity Act (DCA, 2005) came fully into force in England on 1 October 2007, and aims to protect people who cannot make decisions for themselves due to a learning disability, a mental health condition or for any other reason. The Mental Capacity Act sets out rules about how decisions

should be made on behalf of people who cannot make decisions for themselves – described in the Act as people who ‘lack capacity’. The Act states that everyone should be presumed to have capacity to be able to make a decision until it has been proved otherwise. It also states that any decision made on behalf of a person who lacks capacity must be made in the person’s best interests, and that their wishes and feelings must be taken into account.

People with a learning disability are not always treated as individuals who have rights, independence and choice. For example, a gentleman named Alan was repeatedly prescribed medication he constantly told the doctors he did not want and subsequently refused to take. Also not everyone supported through this project knew that their condition was life limiting. It is essential that they are always kept at the centre of decisions made about their own lives.

The Act provides clear guidelines for carers, families and professionals about who can take decisions in which situations. A person’s capacity to make a decision will be established at the time that a decision needs to be made, so this is context specific. The Mental Capacity Act (2005) has provided useful information and is the appropriate tool to be used when seeking guidance around capacity and consent. To summarise, there are five key principles which need to be followed:

1. A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

2. The right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions.
3. Individuals must retain the right to make what might be seen as eccentric or unwise decisions.
4. Best interest – anything done for, or on behalf of, people without capacity must be in their best interests.
5. Least restrictive intervention – anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms.

(Mental Capacity Act, 2005)

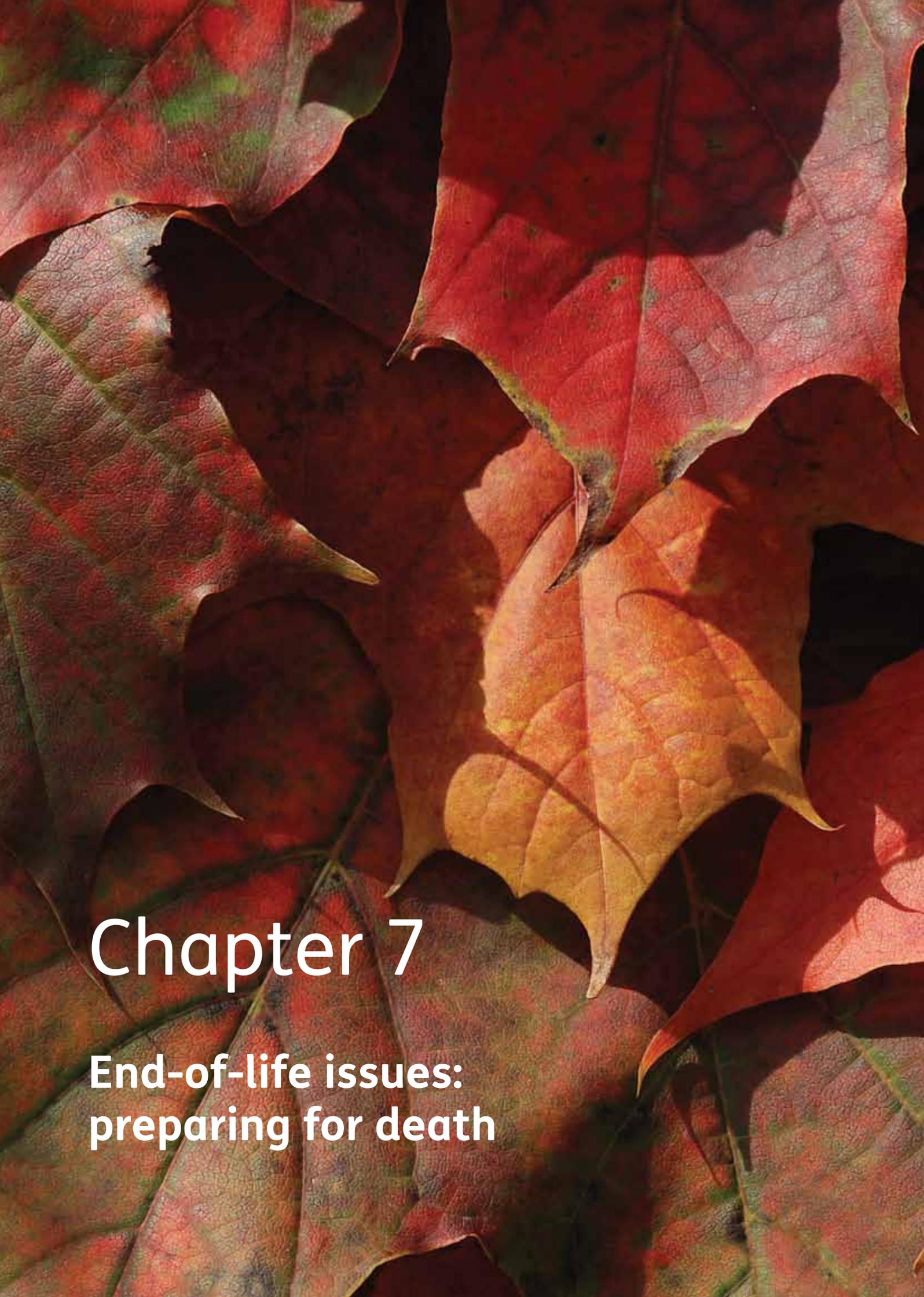
These principles should be considered in the complex decision making process at various points throughout the end-of-life care journey.

The Mental Capacity Act set up the Independent Mental Capacity Advocate (IMCA) service. The service helps vulnerable people who cannot make some (or all) important decisions about their lives. The IMCA service will mean that certain people who lack capacity will be helped to make difficult decisions such as medical treatment choices or where they live. It is aimed at people who do not have relatives or friends to speak for them.

For information about the Mental Capacity Act, please access the government website at: www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/YourRightsInHealth/DG_10016888

Key points

- Some people with a learning disability die without knowing the severity of their illness, or without knowing that their family/friends are dying.
- People with a learning disability must be treated with respect and dignity, and treated as an adult throughout their illness.
- It is essential that people with a learning disability are always kept at the centre of decisions made about their own lives.



Chapter 7

**End-of-life issues:
preparing for death**

Preferred priorities for care

Many individuals may already have considered where they would like to die, even when they are in good health, but not everyone will choose to think or talk about such sensitive issues unless they have to. Hospices are places where specialist palliative care and support is provided, but they carry much stigma, and people with a learning disability (as do some members of the general population) may think they are solely places to die.

“...but when you go there, you die there...”

Woman with cerebral palsy

Not many people with a learning disability will have been encouraged to explore issues of such a sensitive nature (such as loss, death or dying), as part of their everyday lives. End-of-life care must be appropriate to the patient's normal way of life with an emphasis on quality of life (Read and Thompson-Hill, 2008). For the person with a learning disability this will require a collaborative approach by the healthcare professionals involved in their care, but research suggests that such collaborative approaches are often lacking (Todd, 2004; Botsford 2004; Tuffrey-Wijne et al 2007). It is important that such approaches begin from the point that the person's condition is deemed to be life limiting, so that the person is fully

informed from the start. As the condition deteriorates (as, for example, in the case of dementia) the person's capacity to understand will likewise diminish, particularly if the person had limited cognitive abilities to begin with.

Honesty and truthfulness at this time is crucial, with communication the key to effective support.

The DH has endorsed specific tools developed to improve end-of-life care including the Liverpool Care Pathway, the Gold Standards Framework and the Preferred Priorities of Care (previously Preferred Place of Care).

These tools act as a guide or framework to healthcare professionals to ensure that people with end-of-life conditions can be offered choices regarding their care in the last year of life and in the terminal phase of their condition (i.e. the last few days of life). People with a learning disability truly challenge all healthcare professionals involved in the application of these frameworks, since these tools are most effective when reciprocal communication is at its best (Read and Thompson-Hill, 2008).

The successful application of such tools with people with a learning disability is dependent on collaborative approaches across interdisciplinary teams of professionals and families to maximise communication and to meet individual priorities and choices of the individuals involved at the end of life. This has been a successful outcome of the NSPC project, as the project co-ordinator acted as the conduit between generic end-of-life care services and specialist end-of-life care and support. The need for someone, or a team of people, to take the lead for this is important to effective end-of-life care and support for this population.

Making a will

Not everyone will leave explicit instructions about their needs and wants for the funeral and afterwards. However, some people might feel this is very important. People with a learning disability may not be aware that they can make a will, and carers need to provide opportunities to explore this with them in a meaningful way.

People with a learning disability can make valid wills if they have the mental capacity to do so. The capacity required includes the capacity to understand:

- the nature of the document being written
- the extent of the property/items to be disposed of
- the claims of those to be benefited by, or excluded from, the will.

If in doubt, the test of mental capacity to make a will is a legal test and a solicitor with experience in this area should be consulted. Please refer to Mencap's factsheets about making wills. These are available from the wills and trusts team. You can order them by visiting www.mencap.org.uk/willsandtrusts or by calling 020 7696 6996. There are examples of simple questions about making choices known regarding funeral plans and so on (see also Mansfield, Auckland, and Evans, 2006).

Saying goodbye

As death approaches, the person may wish to say goodbye to their friends, families and carers, and every opportunity to help them to do this should be made. Similarly, friends, families and carers

need to be able to say their goodbyes to the person who is dying too. This involves being imaginative in the ways that people with a learning disability want to say goodbye in a meaningful way. If the person is unlikely to live to see Christmas, then the festivities could be brought forward, as was the case with Mark, who was part of the project.

Case example: Mark

Mark was 26, and had non-Hodgkin's lymphoma. He knew that he was dying, since everyone had been open and honest about his illness, its progression and ultimate end. Mark was convinced that he would die before Christmas (he actually died on 27 December 2007, at 5pm). Mark liked Christmas, and had many friends who he enjoyed giving presents to. Mark's friend Jane took him shopping in November, where he bought and wrapped all his presents in time for Christmas. Once the presents were selected, bought and wrapped, Mark decided to give them out to his family and friends as they visited throughout November and December, since he was convinced he would be too ill to do this on Christmas Day. This was important to Mark – he was able to say his 'goodbyes' and 'thank yous' to those who mattered to him, in his own way and in his own time. This was felt to be important to Mark by all those who cared for him.

For any goodbye to be meaningful, the person who is dying needs to be fully aware that death is drawing closer, and this means that carers and families need to remain open and honest about what is happening, however difficult this may be, thus empowering the person to make

decisions about what is important to them, and what they would prefer to do, with those closest to them. For some, it may be the drawing of a picture. Others may need help in selecting and writing cards. Some people might want a living funeral, where everyone comes and says goodbye to the person face-to-face, and celebrates their life with good wine, good food and particular music. In order to make endings appropriate, someone has to ask the person what they would like and what is important to them, and this may be difficult for some family members and carers. If the person has not made any prior decisions about their funeral, carers could try talking to them even at this late stage.

Support for people with a learning disability

When someone is seriously ill or is dying, people around them (such as friends, family, and carers) are needed to offer consistent support, help to the ill person and each other. End-of-life care is not solely about caring for the patient, but about support and includes support and care for family and friends. For many people who have a learning disability, their closest friends may also be people with a learning disability, and they too need help and support in dealing with impending death.

Honesty and openness is important, as individuals will need to know what is happening to their friend as they see their health deteriorating. They need to be able to say their 'goodbyes' in an appropriate way. As death approaches, this process needs to be explained to them in a meaningful way, perhaps using picture books such as the Books Beyond Words

series, for example 'When someone dies', (Hollins, Dowling and Blackman, 2003). Friends should be encouraged to ask questions about their friend who is ill; to visit them if they are in hospital or the hospice; and to express their sadness (and other feelings) as death approaches. If people with a learning disability are actively involved in the circle of support to the dying person, they are less likely to need specialist bereavement counselling and support following the death (Read, 2005). Carers could use this experience to help people with a learning disability to understand about loss, death and dying; to normalise the grief experience; and to help individuals to recognise the importance of individual coping strategies and to learn from their experiences.

Support for friends, family and carers

Empowering someone who is dying throughout their illness and as death approaches is no easy task. Trying to involve the person, supporting them to make decisions about treatments, options, helping the person to make a will, funeral preferences, can be both physically and emotionally draining. As families, friends and carers share the journey towards the end of life, they also share the emotional rollercoaster – when the dying person feels fairly well one day, but deteriorates the next – as treatments are adjusted constantly to meet the progressive illness. Situations may change on a daily basis, and decisions (such as whether to be admitted for hospice care) are made accordingly. Such ongoing support can be very tiring, both physically and emotionally for all those involved.

Holistic end-of-life care is not only about the patient, but incorporates the family and friends too, in recognition of the importance of support for all those involved. Support may be available from the local hospice, from other friends and family, from local carers groups, local learning disability support groups (such as Mencap or the Down's Syndrome Association) and this project.

Case example:

dementia support

‘Dementia is when a person does things in a peculiar way. Well, not ‘funny’ as in peculiar, but oddly. Behaves oddly... your brain slows down.’

Man with a learning disability

In one residential home, where eight people with a learning disability have lived for many years, three of them have been diagnosed with dementia. Some people with a learning disability have a simple understanding of this illness.

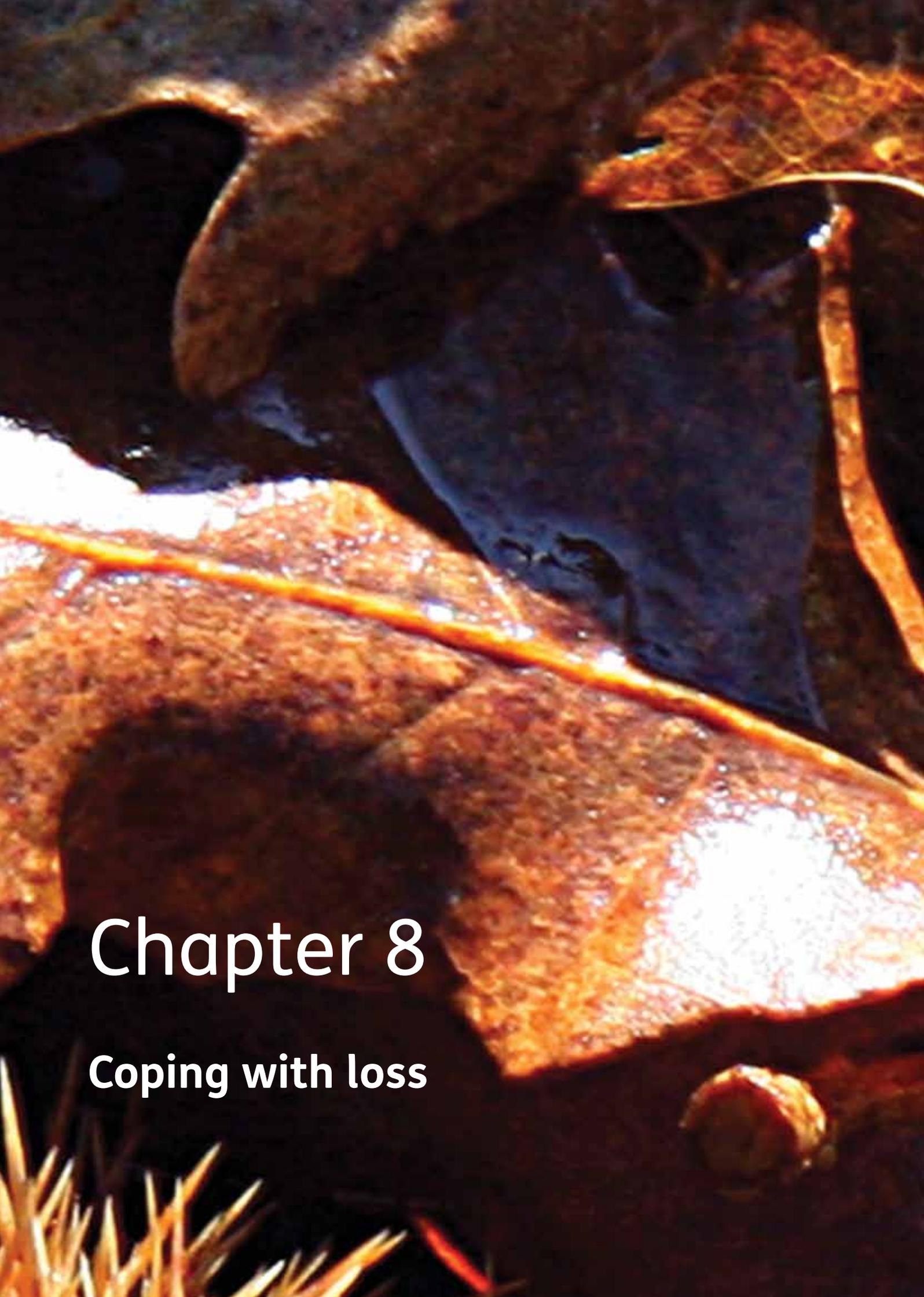
Although they are all at various stages of this progressive disease, their families, friends and professional carers have similar support needs. The project worker arranged to meet them on a regular basis to provide the opportunity for everyone to share his or her concerns within the home settings. Such support was minimal (only meeting monthly for an hour) but highly effective in acknowledging the need for support and giving permission for people to voice fears and anxieties in a safe and confidential environment.

Professional carers should be able to access organisational support, peer supervision, and clinical supervisions as well as accessing any of the general support organisations available. In addition to emotional and psychosocial support, practical support can involve getting help with obtaining aids and appliances, acquiring appropriate benefits, and accessing respite services (learning disability and hospice). Such practical support may not just be for the patient, but can involve the carers, for example, being able to access relaxation activities such as body hand massage. Practical support for professional carers involves resource information; knowing when, where and how to refer patients for specific treatments; help with creative approaches to managing end-of-life care for people with a learning disability. The project worker has been pivotal in working with a range of personal and professional carers throughout the North Staffordshire Palliative Care project, while supporting individuals with their end-of-life conditions.



Key points

- Not many people with a learning disability will have been encouraged to explore issues of such a sensitive nature (such as loss, death or dying), as part of their everyday lives. Carers should talk openly and honestly about all aspects of death and dying while the people they support are well and healthy.
- All people involved in a person's life will need variable support both when a person dies and afterwards.
- As death approaches, the person may wish to say goodbye to their friends, families and carers, and every opportunity to help them to do this should be made.



Chapter 8

Coping with loss

Loss has been described as no longer having what you preferred to keep, and as such can include anything from material objects (keys, photographs), to loss of body image or some aspect of self (having a mastectomy, losing your role for example, as breadwinner to the family); through to the loss of a loved one or significant other relationship (divorce, separation and death), and incorporate developmental losses (those we learn to live with over time, such as moving house (Hess, 1980). Maureen Oswin (2001) described the importance and magnitude of loss when she identified that at any one time people are either experiencing loss, thinking about previous loss experiences, or worried about future or anticipated losses. Sometimes it is a combination of all three. Hence, loss is universal, and people do learn to live with and accommodate the variety of losses inherent in living. Receiving a diagnosis of a life-limiting condition does not automatically mean that death is imminent, but the condition in itself can bring many losses as the person learns to live with the illness and any treatment (and subsequent side effects) that this involves.

Case example: Susan

Susan was diagnosed with a brain tumour when she was 24 and lived with this condition for two and a half years. As the illness progressed, she lost her independence, and could not go shopping when she wanted to without arranging someone to accompany her, because she became prone to seizures. She lived at home with her mother, but required more and more help to maintain their day-to-day living as her headaches increased,

and she became generally weaker. She found this all very frustrating, as the more dependent she became the more she and her elderly mother came to rely on carers and family. She attended day care at the local hospice, initially under sufferance, but she came to like the range of activities offered and the varied friends that she met there. Day care reminded her of her illness; she saw the frailty of some of the people she met there and experienced loss of these friends as some of them died. During the latter part of her illness, she became reluctant to attend day care because she was fearful that she might be admitted to the hospice because of her failing health. Weight loss, hair loss, dependency on treatment (tablets and chemotherapy) and frequent hospital visits for tests and appointments really impinged on her life, her time and her patience. Loss became a reluctant friend throughout this journey, and the Mencap project worker and a counsellor acknowledged these losses and supported Susan throughout her illness until she died at the hospice.

Loss experiences are often life changing yet go unrecognised among people with a learning disability (Bonell-Pascual et al, 1999) and death is usually seen as the ultimate loss, perhaps because of its irreversibility and finality. Carers need to remain alert to the range of potential losses (both obvious, such as hair loss, and hidden, such as dignity and independence) that accompany life-limiting conditions. This is particularly important where people with a learning disability are concerned, since they may not understand why such losses are happening to them as a result of their illness. In some cases they may not even know that they are seriously ill. This is a further reason for professionals and carers to remain open and honest with people with a learning disability when ill health is present.

Bereavement as loss

For the person with a learning disability, the death of their main carer can result in multiple and successive losses (Elliott, 2005) as the person often has to move house, and loses all sense of established social identity, friends, routine and familiarity. Often the future for them is unknown, once services and professional carers become involved and help the person to find a suitable, albeit different, home for the future.

When a friend in the care home, for example, has been ill over a period of time and dies, although not a direct relative, the impact can similarly be huge and the losses multiple. Many people with a learning disability have lived together for some considerable time, with friendships running deep and strong. Following the death of a friend, often the bed is quickly reallocated. Sometimes the dead person is quickly forgotten as life goes on in a deliberate fashion, and meeting a new person who seems to have replaced the deceased compounds the reality of the loss.

Relatives, friends, personal carers and other professionals need to remember that people with a learning disability do experience loss, can express grief and need to be actively involved in the rituals (such as the funeral and other memorials) surrounding the death as much as they want to be. Sadly, for many people with a learning disability, death remains a mystery, perpetuated by carers who prefer to protect individuals from the raw reality of grief, and deliberately excluding individuals from the mourning process.

Yet if people with a learning disability could access appropriate education around loss, death and coping strategies from a proactive perspective and if they

were actively encouraged to participate in grief work and have their grief needs facilitated in an appropriate and reactive way, then it is argued that the need for specific intervention (such as counselling and therapy) would be reduced (Read, 2005).

Similarly, the impact of loss can be huge for those personal family carers, and others in the residential home, day care setting, community nursing service or special school, who may have known the person for some considerable time. Support is crucial for all those involved at this sensitive time, as indicated in the previous section.

Responding to death

“The response to bereavement by adults with a learning disability is similar in type, though not in expression, to that of the general population” (Bonell-Pascual, et al, 1999). However, many people with a learning disability are still not expected to grieve, and often do not have the support from those around them to participate in the rituals surrounding death and the memorials which follow. Cultural and societal taboos make grieving difficult for people with a learning disability and have an adverse effect on the people supporting them as they grieve.

These taboos include:

- general taboos around death and bereavement
- emphatically negative attitudes which Oswin describes as the double taboo of death and disability (Oswin, 1991; 2000)
- low expectations, stereotyping and stigma (Kitching, 1987)

- the complexity of reduced cognitive ability, attention span and limited emotional vocabulary (Conboy-Hill, 1992).

People with a learning disability are vulnerable, as many have an external locus of control, remaining reliant on so many people (often professional carers) for so much, and they are actively excluded from responding to death and dying (Read and Elliott, 2003). There appears to be a factorial effect with people with a learning disability that precludes active involvement in the sad business of death, where the more complex the needs (such as having communication impairment or challenging behaviours), the lower the likelihood they have of being involved (Read and Elliott, 2003).

Additionally, people with a learning disability usually experience sudden, as opposed to anticipatory, grief. This reduces any opportunity for care-givers, staff or counsellors to work towards the death with the dying person, thus minimising any opportunity to say their goodbyes in any meaningful fashion. Carers need to be aware of this so that they can anticipate grief reactions and help support bereaved individuals through their loss.

Challenges to bereavement support

In addition to the cultural and societal taboos that exist generally around death and disability (Oswin, 1991), supporting a bereaved person with a learning disability can be difficult. Negative and somewhat unhelpful attitudes (Oswin, 1991; 2001) have meant that many carers have failed

to recognise the importance of grief work for this population. Parents and professional carers have tended to focus upon the symptoms resulting from the reactions of loss (i.e. changes in behaviour) rather than addressing the cause of loss itself (Crick, 1988), meaning that there is always the possibility that grief reactions will return (Read, 2008).

More than 50% of people with a learning disability may have some form of communication impairment (Kerr et al, 1996), and many lack the appropriate verbal repertoire to express their inner feelings in an articulate, meaningful way. Supporting the person may not be easy, as there may be uncertainty concerning exactly what has been absorbed or indeed understood. Since bereavement counselling is perceived as a “talking therapy”, the combination of limited cognitive ability, attention span and emotional vocabulary (Conboy-Hill, 1992) may make counselling support difficult for some people with a learning disability, and carers may believe such an intervention is inappropriate. Such a range of issues potentially makes grief support complicated or hard to access, many people with a learning disability may not receive the support they need following bereavement and thus may experience disenfranchised grief (Doka, 1989; 2002).

Disenfranchised grief

Doka describes disenfranchised grief as “the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported” (Doka, 1989: 18). Groups likely to experience disenfranchised grief are elderly people, children, people with mental health problems, people with HIV and AIDS, and people with a learning disability. This usually means that:

1. the relationship between the deceased and the bereaved is not recognised
2. the loss is not recognised
3. the griever not recognised (Doka, 1989).

Additionally, the circumstances surrounding the death and the ways that individuals grieve might affect the way that people deal with their loss (Doka, 2002).

Being disenfranchised following a death might intensify the emotional responses to the loss (intensifying feelings of anger, guilt or powerlessness). Many of the factors (such as grief rituals) that facilitate mourning may be missing for disenfranchised grievers. Ambivalent relationships and concurrent life crisis can complicate grief, both of which are present in disenfranchised grief. Ultimately, the very nature of disenfranchised grief precludes emotional support.

Additionally, people with a learning disability may experience disenfranchised death (Read, 2006) because they are deliberately excluded from knowing about their ill health, not involved

in treatment decisions, and remain unaware of their poor prognosis. Indeed some people with a learning disability die without knowing that they were so seriously ill. Everyone will die, and everyone has the right to know when death is imminent, and carers should try and help the person understand this regardless of any disability, once it has been established that the person does want this information. Collusion is an easy trap to fall into with all marginalised groups of people and should be avoided wherever possible.

Facilitating grief: a creative approach

Helping the person who has difficulty in understanding abstract concepts (such as dying and death) can be difficult but is not impossible. Carers need to use straightforward language, avoid euphemisms, and repeat words and phrases often and in a consistent manner. Using photographs, artwork, or visiting cemeteries to take flowers are all useful and concrete ways of making abstract concepts seem real – they can help a person understand what is happening either around them or to them.

When someone is ill and in a hospice, their friends who have a learning disability need simple explanations about what it will be like to visit the hospice, for example, who they will meet or what they will see.

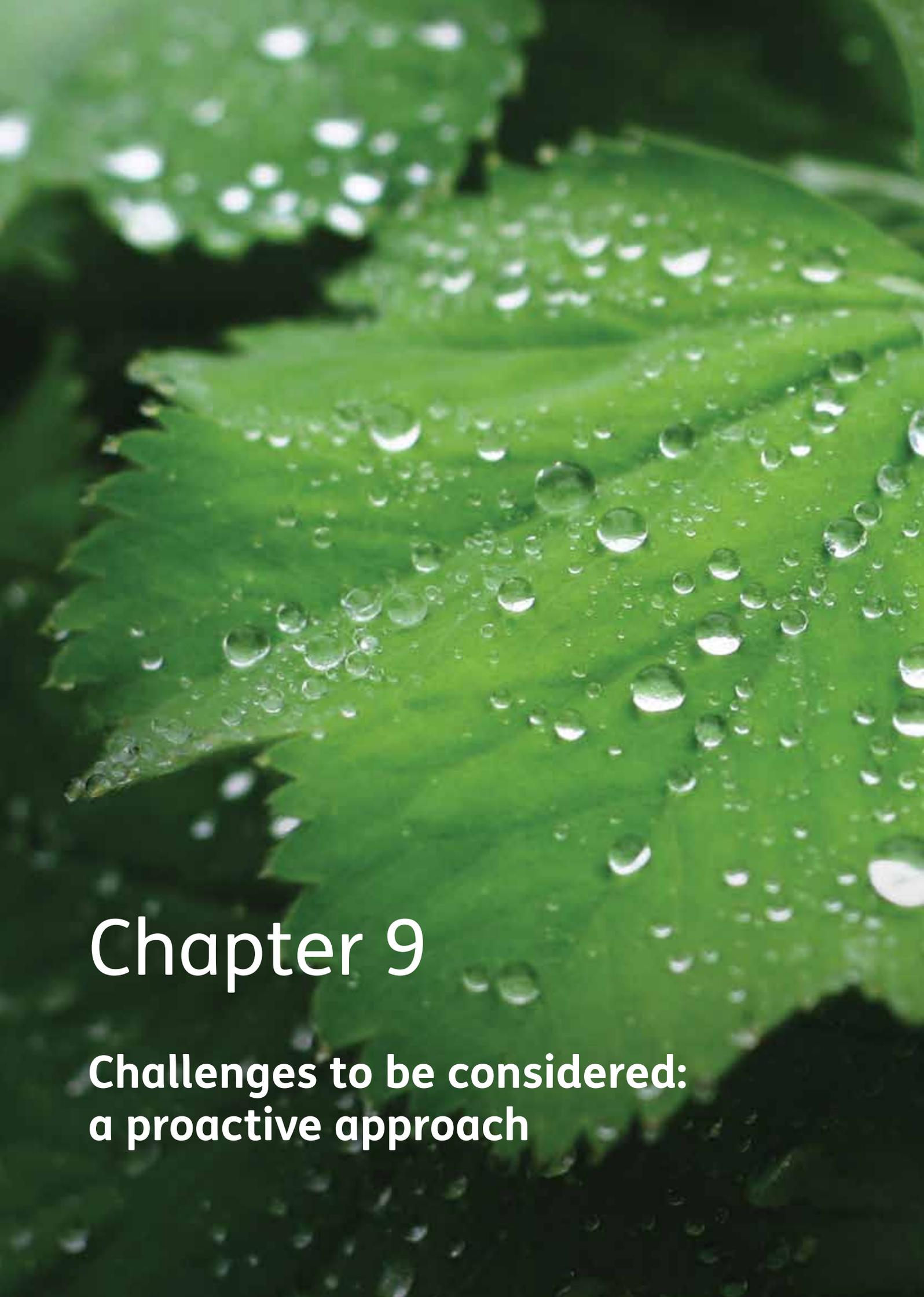
“We need to talk about it... more information”

A woman with learning disability

Carers need to work creatively in order to keep them informed in a regular way using mediums such as picture boards, life story work (Read and Bowler, 2007), photographs, videos, music and artwork to support the person in a meaningful way. Talking with family and friends, and working alongside familiar carers, can provide a clearer picture of the person and help to respond to their needs in a person-centred way. Life-story work may be pivotal to this process.

Key points

- Carers need to remain alert to the range of potential losses (both obvious, such as hair loss, and hidden, such as dignity and independence) that accompany life-limiting conditions.
- When a friend in the care home, for example, has been ill over a period of time and dies, although not a direct relative, the impact can similarly be huge and the losses multiple.
- Helping a person who has difficulty in understanding abstract concepts (such as dying and death) can be difficult but is not impossible.



Chapter 9

**Challenges to be considered:
a proactive approach**

Health promotion: ideas for the future

Work within this project has illustrated the importance of end-of-life care for people with a learning disability. During the time of this short project the project co-ordinator received a total of 35 referrals, many of which involved supporting the whole family, and which incorporated a range of life-limiting conditions, although the majority of which were cancers. People with a learning disability are as prone to the full range of ill-health conditions as the rest of the population, including malignant and non-malignant life-limiting conditions, and cancer was the main reason for referral to this project.

Support for the person with a learning disability who requires end-of-life care can be complex, and early diagnosis remains crucial for effective health outcomes for everyone. However, people with a learning disability often receive a late diagnosis, with an associated poor prognosis (Tuffrey-Wijne, 1997). Some people with a learning disability may recognise their own ill health but may be afraid of doing something about it (as is frequent in the rest of the population) or harbour a fear for hospitals and what they might bring (Tuffrey-Wijne and Davies, 2006). This was also evidenced in the case example of Alan.

Case example: Alan

Alan, a 59-year-old man with a learning disability, didn't like going to the doctors, didn't like being ill and didn't like taking medication. He regularly became breathless, he had an agitated cough, and experienced general discomfort. He ignored these symptoms for many months until his sister and his neighbours eventually persuaded him to go to his GP. His GP made an appointment with the hospital consultant, and he was quickly diagnosed with lung cancer. No active treatment was offered or appropriate, and he died six months later.

While some people with a learning disability recognise their own ill health, many cannot. Families and professional carers have a major role to play in noticing symptoms of potential ill health, and encouraging people to seek out medical advice. Once ill health is noticed, some carers need to be able to help people to access clinics and attend appointments. AWARE (Figure 4) is a useful checklist to remind carers of their role in promoting health with people with a learning disability.

Figure 4: **AWARE:** promoting health with people with a learning disability

Alert people to the potential for ill health. Carers can use videos and booklets to teach people with a learning disability about the possibility of ill health before it happens to them, and also about the role of hospitals, hospices and medical staff. The pictorial Books Beyond Words series (including 'Looking after my breasts' (Hollins & Perez, 2000), 'Keeping healthy down below' (Hollins & Downer, 2000), 'Looking after my heart' (Hollins, Cappuccio & Adeline, 2005), 'Going to the doctor' (Hollins, Bernal & Gregory, 1996), 'Looking after my balls' (Hollins & Wilson, 2004) and 'Getting on with cancer' (Donaghy et al, 2002) are useful, flexible resources designed specifically for people with a learning disability.

Watchful and vigilant: regarding regular personal body checking. Carers need to notice any changes in any aspect of the person that might be an indicator of ill health (for example apathy, loss of weight) and monitor, seeking medical advice when appropriate.

Attempt regular screening programmes. Encourage and support individuals to make use of the opportunities to have health checks such as mammograms, cervical screening, and testicular checking. Identifying disease early can have an impact on treatment and outcomes.

Remember to encourage people to tell someone if they don't feel well or they notice any changes in their body. Talking about such sensitive issues may be difficult, and carers need to give people opportunities to explore how they feel in a way that the person feels most comfortable with (for example using pictures, drama or role play).

Encourage and enable people to attend appointments and to understand the benefits of doing so. Some people may need more time at clinics to help with communication issues; some may need to visit the clinic/hospital prior to the appointment to familiarise themselves with the venue. With the agreement of the person with a learning disability, a familiar carer should accompany the person at appointments to promote consistency of support and minimise distress for the person. Health facilitators might be useful contacts for this process, if available where you live.

Corbett (2007) developed a framework to support hospital admission for people with a learning disability, and some of the factors within this framework can also be useful to support hospital appointments. This includes carers needing to be prepared and having a clearly identified and recorded plan of support needs which will enhance success of any procedure or hospital visit, particularly for people with severe and complex disabilities. Gathering together information prior to the appointment will help carers to identify potential individual support needs. Carers should share information with appropriate professionals as required, with the person's permission, to enable holistic care.

Collaborative working

As is common with many aspects of care for people with a learning disability, working together to meet individual needs will be paramount in providing end-of-life care. The number of professionals potentially involved with an end-of-life diagnosis can be huge and varied – see case illustration, Kath.

Case example: Kath

Kath was a lady with Down's syndrome, aged 54 and she lived with her 60-year-old sister, Marj, three teenage great-nephews and their mother. Kath was diagnosed with dementia following numerous health issues. She only had one lung, which did not contribute to the challenges of dementia but did impact on her physical ill health and deterioration at the end of her life.

There were many professionals involved with Kath and her sister including day service staff, epilepsy specialist nurse, speech therapist, health facilitator, respite unit staff, occupational therapist, social worker, learning disability nurse, district nurse, GP, consultant, non-malignant link nurse, and community care workers who were involved from the early stages of diagnosis. The project co-ordinator was involved throughout.

Marj, the sister, was a pensioner, and was Kath's sole carer with some support from her grandchildren; she slept on a sofa beside Kath's bed, and was there for her throughout her illness from July 2007 until her death in September 2007. As her illness progressed, more support and advice was required, and because the support team was so large, they all

met initially once each month at the day service, to ensure that the needs of Kath and Marj were met. Eventually, the meetings were weekly, as her changing health status was more frequent. The co-ordinator called on alternative days to ensure continuing psychological and practical support. By this time Kath could not communicate verbally at all. Marj acted as interpreter for her daily needs.

One evening in September, Kath deteriorated very quickly, emergency services were called and she was subsequently admitted to the medical assessment unit of the local hospital, where she stayed for two days before being transferred to a ward where she died five days later. She was admitted to a side room, where all her relatives and friends could sit with her privately until she died.

While there were numerous professionals involved throughout Kath's care, it was important to ensure effective communication channels between the professionals, the family and the patient remained in place, with Kath remaining at the centre of the discussions regarding her treatment and care. Carers need to work alongside these professionals in a deliberate manner while not losing sight of the person who is at the centre of the care received. Best interest discussion groups are helpful in formally bringing professionals, carers and the person who is ill, who all share the common goal of identifying what is the best course of action for the person involved. Advocates too have an important role in this process.

This project has illustrated the importance of effective collaborative working (with health and social care professionals such as specialist end-of-life care nurses and doctors, social workers,

Developing links

‘I think we can be a bit insular – we are within our own fields...we don’t communicate. We need to integrate and communicate with each other and offer education.’

Health facilitator

physiotherapists, occupational therapists, health facilitators and advocates) and the need to be proactive in forging links with organisations akin to supporting end-of-life care developments. For example, in North Staffordshire, professionals in one hospice and one learning disability service are currently spending time in each other’s organisation to gain insight into their relative organisation in the effort to forge links and establish good working relationships in the future. These developments are a direct result of the project’s work, and are hallmarks of good practice in end-of-life care for people with a learning disability, which will be formally evaluated.

The launch of the project and the five focus groups that ran throughout the project, while helping to shape the direction of the work and the content of this best practice guide, also enabled individuals to meet and forge links across professional boundaries so that the participants involved could exchange contact details. Ideally, directories and contact details of relevant professionals and organisations should be compiled before people become seriously ill, as was highlighted in all of our professional

focus group discussions. They also need to be dynamic and regularly updated. Such activities also help raise the profile of this marginalised group among organisations that hitherto did not recognise it.

‘The sad thing for people with a learning disability is that you only become an expert when it is happening to you...’

Learning disability carer

Research: the route to good practice

‘...it’s a matter of pot luck really...’

A family carer

Empirical research around end-of-life care specifically for people with a learning disability remains patchy, hence service provision is often perceived as ‘pot luck’. This best practice guide is founded upon the direct experiences of the North Staffordshire Palliative Care Project and as such is evidenced based. Such a guide will contribute to the limited but growing literature of practical support in this arena.

However, baseline statistical data of the numbers of people with a learning disability who have malignant and non-malignant, palliative conditions remains poor. Professionals need to ascertain the nature, frequency, and type of conditions experienced; and the specific illness trajectories of disease progression with this population. Researchers also need to work alongside parents and carers to share the ‘lived’ experiences and journeys of their illnesses; to identify when and where help is required and which interventions are found to be the most effective. Ultimately, professionals need to be talking, listening and hearing the words of people with a learning disability themselves in order to ascertain, appreciate and understand their views and perspectives upon this sensitive area of care.

To keep this best practice guide grounded in practice, a checklist has been developed that will enable learning disability and end-of-life care organisations to monitor and evaluate their end-of-life care service provision for people with a learning disability in a systematic way. This checklist (figure 5) was originally published in 2003, and the project work has helped to affirm these important points and build on the existing points. It can be used initially as a baseline measurement against which future repeated evaluations can be compared. It has been deliberately written to be applicable to end-of-life care, nursing and learning disability services.

Figure 5: a checklist for positive end-of-life practice for people with a learning disability

(after Read, 2003)

The following checklist can be used to evaluate end-of-life care service provision in various professional caring environments.

1	Is your organisation welcoming of people with a learning disability who require end-of-life care?	<input type="checkbox"/> Y	<input type="checkbox"/> N
a	Are your signs easy to read and follow?	<input type="checkbox"/> Y	<input type="checkbox"/> N
b	Are your information sources available in clear and easy-to-understand versions?	<input type="checkbox"/> Y	<input type="checkbox"/> N
2	Are you aware of any barriers to providing end-of-life care for people with a learning disability within your organisation?	<input type="checkbox"/> Y	<input type="checkbox"/> N
3	Are any of the staff team identified as taking the lead role in end-of-life care?	<input type="checkbox"/> Y	<input type="checkbox"/> N
4	Are any of the staff team identified as taking the lead role in learning disability?	<input type="checkbox"/> Y	<input type="checkbox"/> N

5	Do your staff team adopt a proactive approach to talking about loss, death and dying in your organisation?	<input type="checkbox"/> Y	<input type="checkbox"/> N
6	Do you have a system that ensures that carers actively look for changes in the health status of people in their care?	<input type="checkbox"/> Y	<input type="checkbox"/> N
7	Do you have easy access to a resource base (books, videos, leaflets etc) around end-of-life care?	<input type="checkbox"/> Y	<input type="checkbox"/> N
8	Do you have easy access to a resource base (books, videos, leaflets etc) around learning disability?	<input type="checkbox"/> Y	<input type="checkbox"/> N
9	Do you have access to a resource directory regarding how and where to access information about end-of-life care for people with a learning disability?	<input type="checkbox"/> Y	<input type="checkbox"/> N
10	Does anyone from the local palliative care networks (for example Macmillan nurse, Marie Curie nurse, hospice, clergy) liaise with the staff team?	<input type="checkbox"/> Y	<input type="checkbox"/> N

11 Does anyone from the staff team liaise with the local palliative care networks (for example Macmillan nurse, Marie Curie nurse, hospice, clergy)? Y N

12 Do you have any guidelines or policies regarding end-of-life care provision for people with a learning disability? Y N

13 Do you have any guidelines or policies regarding bereavement support for people with a learning disability? Y N

14 Do you have a planned approach to support people with a learning disability attending for diagnostic tests and procedures? Y N

15 Do you have access to information about and contact details for different cultural, religious and ethnic groups within your locality? Y N

16 Do you have guidelines or policies around breaking bad news to people with a learning disability? Have professionals undertaken training in this area? Y N

17 Are families/personal carers involved in end-of-life care and support where the person with a learning disability wants this? Y N

18 Does your organisation have staff who can support individuals to make decisions around treatment even if there is doubt they lack the full capacity to do so? Y N

a Do you have designated people to do this? Y N

b Do you have systems to record this? Y N

19 Are individuals in your organisation able to support people with a learning disability to make choices regarding funeral plans? Y N

Is this recorded? Y N

20 Are individuals within your organisation able to determine a person's preferred place for care/death if the person has a learning disability? Y N

Is this recorded? Y N

21 Is there a named person in your organisation who is ultimately responsible for ensuring that people with a learning disability have access to quality end-of-life care? Y N

22 Do staff have access to regular training around end-of-life care for people with a learning disability? Y N

23 Do you have appropriate support systems in place to support those (both personal and professional) providing care and support for the person with a learning disability receiving end-of-life care? Y N

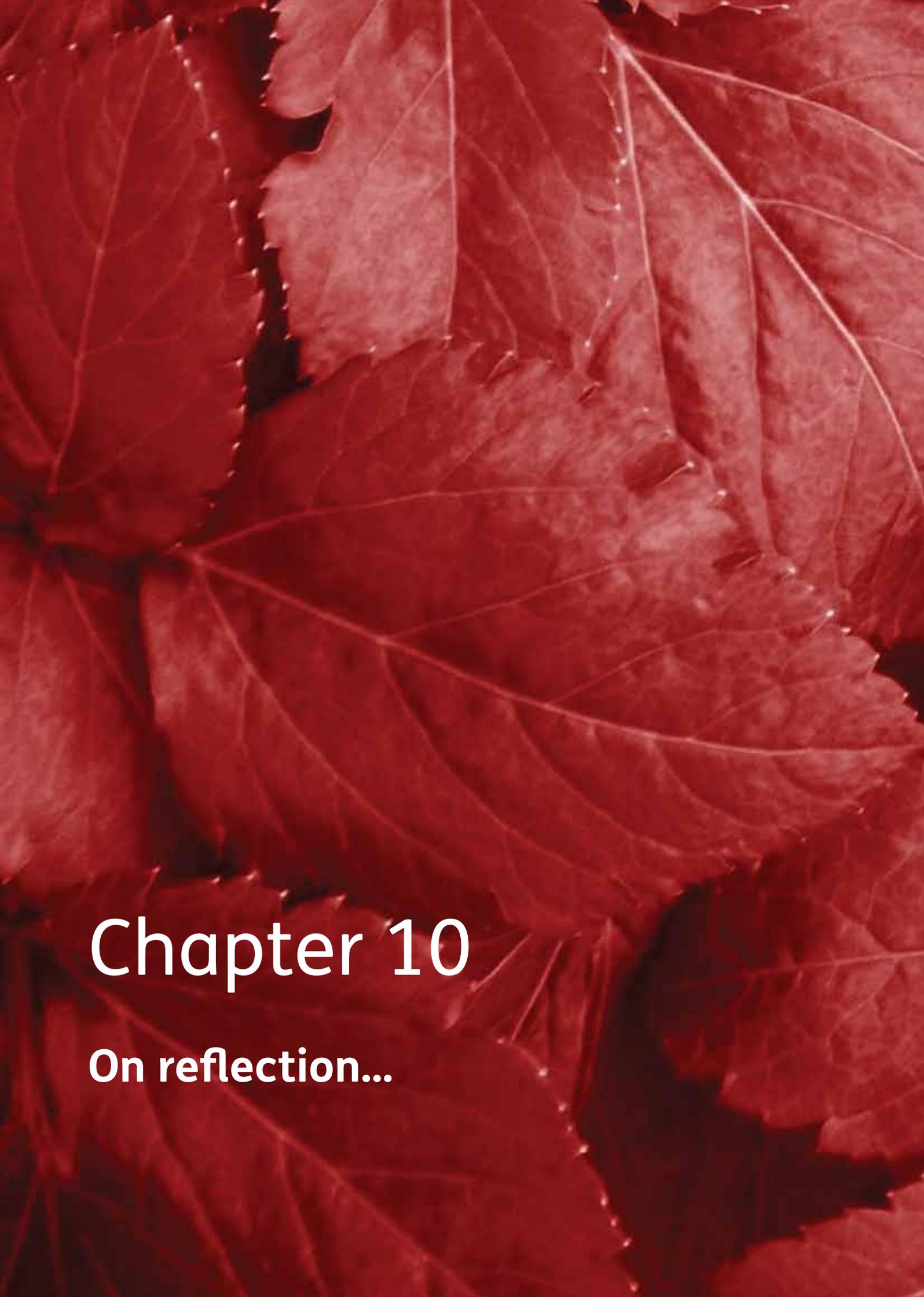
24 Do you have systems in place to ensure that you have done everything practical and feasible to identify and meet the end-of-life care needs of the person with a learning disability? Y N

25 Is there a monitoring system in place to regularly and systematically review end-of-life care provision for people with a learning disability? Y N

Is there a designated person responsible for this? Y N

Key points

- Some people with a learning disability may recognise their own ill health but may be afraid of doing something about it.
- End-of-life care and support is delivered by many different people, and professionals must ensure they work together effectively.
- The checklist can be used initially as a baseline measurement against which future repeated evaluations can be compared. It has been deliberately written to be applicable to palliative care, nursing and learning disability services.
- Every person involved in end-of-life care must always do their very best to give every person with a learning disability the support they deserve and need.



Chapter 10

On reflection...

Providing quality end-of-life care for people with a learning disability can be difficult, and organisations such as the National Network of Palliative Care for People with Learning Disabilities have been pivotal in highlighting the inherent challenges involved over the last decade. Following on from Mencap's Treat me right! and Death by indifference campaign reports (Mencap 2004; 2007), the North Staffordshire Palliative Care Project is perceived as a model for positive practice, highlighting the need for networking, collaborative working and interdisciplinary support.

This best practice guide is the culmination of two years' working together to ensure that people with a learning disability diagnosed with a life-limiting condition (and their family and friends) could access and receive the end-of-life care, support and treatment they needed at the time and place they wanted it. The social context in which death and dying occur will always shape and influence the very core of these events. Indeed, all people involved in a person's life will need variable support both when the person dies and afterwards. Therefore, working with families and friends remained an important aspect of this work.

The two authors have worked together on many projects for many years, but this has been one of the hardest, yet most enjoyable, journeys they have had the pleasure of being involved in.

This journey has been a wonderful opportunity to learn from others, some of whom sadly are no longer here to teach us the way forward. At times the journey has been hazardous, lacking appropriate signposts and directions. But the 'views' along the way have been a tremendous learning opportunity.

Champions usually instigate, lead and direct good practice initiatives, but unfortunately progress can still be fragile across geographical regions. All professional carers involved in end-of-life care and/or learning disability have a professional responsibility to do the best they can to support people at the end of their lives. Sometimes policies and guidelines are simply not enough, and this is why this guide has included the checklist for positive end-of-life care practice (figure 5 in chapter 9) to help to ensure that professional groups can measure the effectiveness of their organisations and have goals to aim for and achieve.

**In the early stages - hope for a cure.
Later - hope for control, hope for comfort.
At the end - hope for peace.**

(Regnard, cited in: Fitzpatrick, 2003:45)



**Resources, publications
and references**

Organisations

Mencap

Provides a range of support services, advice and information for people with a learning disability, their families and professionals and campaigns for the changes people with a learning disability want.

123 Golden Lane
London
EC1Y 0RT
Tel: 020 7454 0454
www.mencap.org.uk

Learning Disability Helpline (in England)

Tel: 0808 808 1111

Mencap Cymru

31 Lambourne Crescent
Cardiff Business Park
Llanishen
Cardiff
CF14 5GF
Tel: 029 2074 7588

Wales Learning Disability Helpline

Tel: 0808 808 1111 300

Mencap in Northern Ireland

Segal House
4 Annadale Avenue
Belfast BT7 3JH
Tel: 028 9069 1351

Mencap's Information Service (in Northern Ireland)

Tel: 0808 808 1111

British Institute of Learning Disabilities (BILD)

Advice and support for people with a learning disability. Training and information for professionals, advocacy groups and carers.

Campion House
Green Street
Kidderminster
Worcestershire
DY10 1JL
Tel: 01562 723 010
www.bild.org.uk

Carers UK

Offers advice and information to carers through its range of publications and network of local support groups.

20 Great Dover Street
London
SE1 4LX
Tel: 020 7378 4999
www.carersuk.org

Down's Syndrome Association

Focuses solely on all aspects of living successfully with Down's syndrome.

Langdon Down Centre
2A Langdon Park
Teddington
TW11 9PS
Tel: 0845 230 0372
www.downs-syndrome.org.uk

Help the Hospices

The national charity for the hospice movement offering advice and information for professionals and carers.

Hospice House
34-44 Britannia Street
London
WC1X 9JG

Tel: 020 7520 8222
www.helpthehospices.org.uk

Foundation for People with Learning Disabilities

National charity working to improve the lives of people with a learning disability through research and community services.

9th Floor, Sea Containers House
20 Upper Ground
London
SE1 9QB

Tel: 020 7803 1100
www.learningdisabilities.org.uk

Macmillan Cancer Support

Support, advice and nursing care for people living with cancer.

89 Albert Embankment
London
SE1 7UQ

Tel: 020 7840 7840
www.macmillan.org.uk

Marie Curie Cancer Care

Marie Curie nurses provide free end-of-life care to patients with cancer and other terminal illness, allowing them to die with dignity in their own homes.

Marie Curie Cancer Care England

89 Albert Embankment
London
SE1 7TP

Tel: 020 7599 7777
www.mariecurie.org.uk

Marie Curie Cancer Care Wales

Block C Mamhilad House
Mamhilad Park Estate
Pontypool
Torfaen
NP4 0HZ

Tel: 01495 740 827

Marie Curie Cancer Care Scotland

14 Links Place
Edinburgh
EH6 7EB

Tel: 0131 561 3900

Marie Curie Cancer Care Northern Ireland

60 Knock Road
Belfast
BT5 6LQ

Tel: 028 9088 2060

NHS End of Life Care Programme

Website aimed at health and social care staff, providing good practice, resources and information on a variety of aspects relating to end-of-life care.

Programme office
3rd Floor, St John's House
East Street
Leicester
LE1 6NB
Tel: 0116 222 5103
www.endoflifecare.nhs.uk

The National Autistic Society

Champions the rights and interests of all people with autism to ensure that they receive quality services appropriate to their needs.

393 City Road
London
EC1V 1NG
Tel: 020 7833 2299
www.nas.org.uk

National Council for Palliative Care

The representative body for those providing, commissioning and using adult palliative care and hospice services in England, Wales and Northern Ireland.

The Fitzpatrick Building
188-194 York Way
London
N7 9AS
Tel: 020 7697 1520
www.ncpc.org.uk

National Forum of People with Learning Difficulties

Works with the Learning Disability Task Force and informs the government how Valuing People is working for people with learning difficulties.

c/o PO Box 2100
Shoreham-by-Sea
West Sussex
BN43 5UG
Email: info@nationalforum.co.uk
www.nationalforum.co.uk

National Network for the Palliative Care of People with Learning Disabilities

A national resource, established by a small group of practitioners from either learning disability or palliative care services, to address the palliative care needs of people with a learning disability.

Dr Irene Tuffrey-Wijne, Chair
Tel: 07977 260 967 (NNPCPLD)

Scottish Consortium for Learning Disability

The Adelphi Centre
Room 16
12 Commercial Road
Glasgow
G5 0PQ
Tel: 0141 418 5420
www.sclld.org.uk

Scottish Partnership for Palliative Care

Works to ensure that people in Scotland with a progressive life-threatening condition receive good palliative care.

1A Cambridge Street
Edinburgh
EH1 2DY

Tel: 0131 229 0538

www.palliativecarescotland.org.uk

Sue Ryder Care

Provides compassionate care and support for people living with serious illnesses and conditions, as well as their families and loved ones.

2nd Floor
114-118 Southampton Row
London
WC1B 5AA

Tel: 020 7400 0440

www.sueryder.org.uk

Publications

‘Advice for hospitals and health professionals’

Mencap (April 2008)

Short page of tips for healthcare professionals when treating people with a learning disability. Download at www.mencap.org.uk/resources and look under ‘publications’.

‘An Ordinary Death’

The Foundation for People with Learning Disabilities (Feb 2003)

And update about the service needs of people with a learning disability who are dying. Free to download at www.fpld.org.uk/publications and look under publications 020 7803 1101 (minimum order £25).

‘Books Beyond Words’

A series of 26 picture books for people with a learning disability covering issues such as screening, going to the doctor, getting on with cancer and what to do when someone dies.

All books are £10. Buy online from Royal College of Psychiatrists’ website at www.rcpsych.ac.uk/publications/bbw or contact College Book Sales office on 020 7235 2351 ext 146 (9.30am to 2pm).

‘Communication for person centred planning, 2005’

This information pack was designed to help staff, self advocates, families and friends to make communication better.

Free to download at www.learningdisabilities.org.uk/publications and look under publications or call 020 7803 1101 (min order £25)

‘Cancer and People with Learning Disabilities’

James Hogg, John Northfield and John Turnbull, 2001, £12

A BILD report, commissioned by the Department of Health, reviewing current knowledge and practice for professionals and organisations delivering care to children and adults with a learning disability. Order from BookSource, 50 Cambuslang Road, Cambuslang, Glasgow G32 8NB or call 0845 370 0067 or order online at www.bild.org.uk

‘Cancer and You’

A toolkit for working with people with a learning disability, Kate Provan, Trafford.

Free to download at www.valuingpeople.gov.uk and look under primary health care.

‘Disdat tool’

St Oswald’s hospice (April 2008)
Disdat is a distress assessment tool designed by St Oswald’s Hospice. It is designed to help health professionals identify distress signs in people who because of cognitive impairment or physical illness have severely limited communication. Download the guide and tool at www.mencap.org.uk/resources and look under ‘publications’.

‘EasyHealth website’

The EasyHealth website has guides for people with a learning disability on health issues and for professionals in treating people with a learning disability.
www.easyhealth.org.uk

‘Equal Treatment: Closing the Gap’

Disability Rights Commission (2006)
A formal investigation into physical health inequalities experienced by people with a learning disability and/or mental health problems. Download part one free at www.equalityhumanrights.com and look under publications

‘Death by indifference’

Mencap (2007)
Report about institutional discrimination within the NHS, and people with a learning disability getting poor healthcare. Download a standard version or an easy read version at www.mencap.org.uk/deathbyindifference. To order printed copies please email publications@mencap.org.uk

‘Dying Matters’

The Foundation for People with Learning Disabilities, March 2005. £25
A workbook for support staff and managers in learning disability services to help them address the needs of people with a learning disability who are dying
To order a copy call 020 7803 1101 (minimum order £25)

‘End of Life Care’

Lynn Gibson & Dorothy Matthews, NHS End of Life Care Programme/NHS North East (2007). A resource pack for those caring for or supporting people with a learning disability at the end of life. Download for free at www.endoflifecareforadults.nhs.uk/eolc/eolcpub.htm

‘Everybody Needs Toilets: an easy guide for people with a learning disability (2006)’

Alice Bradley, Mary Buchanan, John Dawson and Agnes Forsyth, £8
This illustrated easy-to-read booklet is for people with a learning disability who find it difficult to talk about any problems they have with going to the toilet.
Order from BookSource, 50 Cambuslang Road, Cambuslang, Glasgow G32 8NB or call 0845 370 0067 or order online at www.bild.org.uk

‘Good practice in learning disability nursing’

Department of Health (2007)
A guide for health and social care professionals. Download free at www.dh.gov.uk and look under publications or order from Department of Health Publications, PO Box 777, London SE1 6XH
or call 0870 600 55 22
or email doh@prolog.uk.com

‘Guidance for nursing staff’ (Royal College of Nursing)

Royal College of Nursing (April 2008)
A 20-page guide to support nurses treating people with a learning disability. Download at www.mencap.org.uk/resources and look under ‘publications’

‘Healthcare for All’

<http://valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=2102>
Sir Jonathan Michael (July 2008)
Independent inquiry into access to healthcare for people with a learning disability. Download for free at www.iahpld.org.uk

‘Hospitals and healthcare professionals checklist’

Mencap (April 2008)
This is a checklist put together by Mencap, with the help of doctors, for medical professionals who are treating a person with a learning disability to go through to make sure they are meeting their patients needs. Download at www.mencap.org.uk/resources and look under ‘publications’

‘The hospital communication book’

Surrey Learning Disability Partnership Board (April 2008)
Developed by Mencap with the Surrey Learning Disability Partnership Board, this is a practical guide to help people who have difficulty communicating get an equal service in hospital. Download at www.mencap.org.uk under professionals/health/tools

‘How to complain about medical treatment’

Mencap (April 2008)
Mencap’s Death by indifference report shows that people with a learning disability too often don’t get the care they need in the NHS. But there are ways to complain if you are worried about treatment. Download at www.mencap.org.uk/resources and look under ‘publications’.

‘Let’s Talk About Death’

Karen Watchman
A book supporting an adult with a learning disability when someone close to them has died. There is a tape available that accompanies the book. Download from www.dsscotland.org.uk/publications/learning-disability or write to Downs Syndrome Scotland, 158-160 Balgreen Road, Edinburgh EH11 3AU
or call 0131 313 4225.

‘Seeking Consent: working with people with learning disabilities’

Department of Health (2001)
Aimed at those involved in the treatment or care of people with a learning disability. Download free at www.dh.gov.uk and look under ‘publications’ or order from Department of Health Publications, PO Box 777, London SE1 6XH or call 0870 600 55 22 or email doh@prolog.uk.com

‘Living with an illness that I will die from’ The puzzle of palliative care

Palliative care and people with Learning Disabilities (2009).
A series of four leaflets for people with a learning disability; a 16-page booklet for carers; a 20-page booklet for professionals offering palliative care and support. Freely available from Dr Sue Read: s.c.read@nur.keele.ac.uk

‘Palliative Care and People with learning disabilities’

Scottish Partnership for Palliative Care (July 2003)
A report from a one-day conference on 11 February 2003 to examine and reflect on the issues of palliative care and its provision for people with a learning disability. Download free at www.palliativecarescotland.org.uk/publications/index.htm

‘Services for people with learning disability and challenging behaviour or mental health needs’

(Mansell report – revised edition 2007)

Department of Health (2007)
This good practice guidance for health and social care professionals sets out the actions to effectively meet the needs of people with challenging behaviour. Download free at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_080129 or order from Department of Health Publications, PO Box 777, London SE1 6XH. or call 0870 600 55 22 or email doh@prolog.uk.com

‘Shaping the future: A vision for Learning Disability Nursing.’

London, Northway R, Hutchinson C and Kingdon A (eds) (2006). UK Learning Disability Consultant Nurse Network. Download at www.ntw.nhs.uk/uploads/documents/doc203.pdf

‘Taking Good Care’ booklet

Supporting people with a learning disability to be breast aware. Breast Cancer Care (2008)
Tel: 0845 092 0808

‘Treat me right!: better healthcare for people with a learning disability.’

Mencap (2004)

Easy read campaigning report calling for better healthcare for people with a learning disability. Download at www.mencap.org.uk/resources and look under ‘publications’.

To order a printed copy please email publications@mencap.org.uk

‘Valuing People. A new strategy for disability for the 21st century.’

Department of Health (2001)

Aimed at professionals. Download free at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4008274 or order from Department of Health Publications, PO Box 777, London SE1 6XH. or call 0870 600 55 22 or email doh@prolog.uk.com

‘Your Good Health’

A series of illustrated booklets written by health professionals to inform people with a learning disability about health issues and explain how to get help for a variety of health issues. Priced at £8 each. Titles include ‘Getting Older – Feeling Good’ (2004) and ‘If You Are Ill...’ (1998). Order from BookSource, 50 Cambuslang Road, Cambuslang, Glasgow G32 8NB or call 0845 370 0067 or order online at www.bild.org.uk

References

- Ambalu, S. (1997). Communication. In O'Hara, J. & Sperlinger, A. (1999) 'Adults with learning disabilities: A practical approach for health professionals' Chichester: John Wiley & Sons.
- Botsford, A.L. (2000). Integrating end of life care into services for people with an intellectual disability. 'Social Work Health Care', 31(1), 35-48.
- Bonell Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedwick P., Abdelnoor, A. & Hubert, J. (1999). Bereavement and grief in adults with learning disabilities. 'British Journal of Psychiatry', 175, 348-350.
- Brown, H., Burns, & S. Flynn, M. (2003). 'Please don't let it happen on my shift!' Supporting staff who are caring for people with learning disabilities who are dying. 'Tizard Learning Disability Review', 8(2), 32-41.
- Buckman, R. (1984). Why breaking bad news is difficult. In R. Buckman (1992) 'How to break bad news: A guide for health care professionals'. London: Papermac, (11-31).
- Conboy-Hill, S. (1992). Grief, loss and people with learning disabilities. In A. Waitman, & S. Conboy-Hill, (Edits.) (1992) 'Psychotherapy and mental handicap'. (pp.150-170) London: Sage Publ.
- Corbett, J. (2007). 'Health care provision and people with intellectual disabilities: A guide for health professionals'. West Sussex: Wiley & Sons.
- Crick, L. (1988). Facing grief. 'Nursing Times', 84 (28), 61-62.
- Department of Constitutional Affairs (2005) Mental Capacity Act. London: HMSO.
- Department of Health (2001). 'Valuing people: A new strategy for learning disability for the 21st century'. London: DoH
- Department of Health (2008). End of life strategy: Promoting high quality palliative care for all adults at the end of life. London: DoH
- Donaghey, V. Bernal, J., Tuffrey-Wijne, I. & Hollins, S. (2002). 'Getting on with cancer'. London: Gaskell /St George's Hospital Medical School.
- Doka, K.J. (1989). 'Disenfranchised grief: Recognising hidden sorrow'. Toronto, Canada: Lexington Books.
- Doka, K.J. (Edit.) (2002). 'Disenfranchised grief: New directions, challenges and strategies for practice'. Illinois: Research Press.
- Elliott, D. (1995). Helping people with learning disabilities to handle grief. 'Nursing Times', 91(43), 27-29.
- Fitzpatrick, J. (2003). 'Palliative care for people with learning disabilities'. Edinburgh: SHS Trust.
- Foley, D.C. & McCutcheon, H. (2004). Detecting pain in people with an intellectual disability. 'Accident & Emergency Nursing', 12, 196-200.
- Frey, M. (2006). Special needs require special measures. 'Community Living', 20(2), 22-23.
- Gates, B. (2006). 'Care planning and delivery in intellectual disability nursing'. Oxford: Blackwell Publ.
- Govier, I. (2000). Spiritual care in nursing: A systematic approach. 'Nursing Standard', 14(17): 32-6.

- Hatton, C, Turner, S, Shah, R, Rahim, N, Stansfield, J. (2004). 'What about faith? A good practice guide to meeting the religious needs of people with learning disabilities'. London: Foundation for People with Learning Disabilities.
- Hess, P. (1980). 'Nursing and the concept of loss'. London: John Wiley & Sons.
- Higginson, I.J. (2003). Priorities and preferences for end of life care in England, Wales and Scotland. National Council for Palliative Care.
- Hollins, S., & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. 'British Journal of Psychiatry', 170, 497-501.
- Hollins, S., Attard, M.T., von Fraunhofer, N. McGuigan, S. & Sedgewick, P. (1998). Mortality in people with learning disability: Risks, causes and death certification findings in London. 'Development of Medical Child Neurology', 40: 50-6.
- Hollins, S. Bernal, J. & Gregory, M. (1996). 'Going to the doctor'. London: Gaskell and St George's Hospital Medical School.
- Hollins, S. & Perez, W. (2000). 'Looking after my breasts'. London: Gaskell and St George's Hospital Medical School.
- Hollins, S. & Downer, J. (2000). 'Keeping healthy 'down below''. London: Gaskell and St George's Hospital Medical School.
- Hollins, S., Dowling, S. & Blackman, N. (2003). 'When somebody dies'. London: Gaskell and St George's Hospital Medical School.
- Hollins, S. & Wilson, J. (2004). 'Looking after my balls'. London: Gaskell and St George's Hospital Medical School.
- Hollins, S., Cappuccio, F. & Adeline, P. (2005). 'Looking after my heart'. London: Gaskell and St George's Hospital Medical School.
- Jackson, S. & Read, S. (2008). Providing appropriate health care for people with intellectual disabilities. 'British Journal of Nursing', 17(4), S6-10.
- Jenkins, R. (2005). Older people with learning disabilities. Part 2: Accessing care and the implications for nursing practice. 'Nursing Older People', 17(1), 32-35.
- Keenan, P. & McIntosh (2000). Learning disabilities and palliative care. 'Palliative care today', IX ,(1) :11-13.
- Kerr, M., Fraser, W. & Felce, D. (1996). Primary healthcare for people with a learning disability. 'British Journal of Learning Disabilities', 24(1): 2-8.
- Lindop, E. & Read, (2000). District nurses' needs: palliative care for people with learning disabilities. 'International Journal of Palliative Nursing', 6(3):117-22.
- Kitching, N. (1987). Helping people with mental handicaps cope with bereavement: A case study with discussion. 'Mental Handicap', 15, 61-63.
- Macmillan Cancer Support (2003) 'Barriers to accessing cancer services. The report of the Barriers to Access Project Steering Group (Nov 2002-2003)'. London: Macmillan Cancer Support.
- Mansfield, M., Aukland, P. & Evans A. (2006). 'When someone dies'. Cambridge: Speaking up.
- Matousova-Done, Z. & Gates B. (2006). The nature of care planning and delivery in intellectual disability nursing. In: B. Gates (2006). 'Care planning and delivery in intellectual disability nursing'. Oxford: Blackwell Publ. (p: 1-20).
- Mencap (2004). 'Treat me right!' London: Mencap.
- Mencap (2007). 'Death by indifference'. London: Mencap.

- Michael, J. (2008). 'Healthcare for all: Independent inquiry into access to healthcare for people with learning disabilities'. London: Aldrick Press.
- O'Kelly & O'Kelly (2006). 'Chasing daylight: How my forthcoming death transformed my life'. McGraw Hill.
- Oliviere D. & Monroe, B. (2004). 'Death, dying and social differences'. Oxford: Oxford University Press.
- O'Nians, R. (1993). Support in grief. 'Nursing Times', 89 (50), 62-64.
- Oswin, M. (1991). 'Am I allowed to cry?' London: Souvenir Press.
- Oswin, M. (2000). 'Am I allowed to cry?' (2nd Edit) London: Souvenir Press.
- Parkes, C.M. (1996). 'Bereavement: Studies of grief in adult life', (3rd Edit). London: Routledge.
- Payne, S., Seymour, J. & Ingleton, C. (2004). 'Palliative care nursing: Principles and evidence for practice'. Berkshire: Open University Press.
- Read S. (1998). The palliative care needs of people with learning disabilities. 'International Journal of Palliative Nursing', 4(5), 246- 251.
- Read, S. & Elliott, D. (2003). Death and learning disability: A vulnerability perspective. 'The Journal of Adult Protection', 5(1): 5-14.
- Read, S. (2003). Bereavement and loss. In: Markwick, A. & Parrish, A. (2003). 'Learning Disabilities: themes and perspectives'. (pp 81-110). London: Butterworth Heinemann.
- Read, S. (2005). Palliative care for people with learning disabilities: Recognizing pitfalls and exploring potential. 'International Journal of Palliative Nursing', 11(1), 15-20.
- Read, S. & Elliott, D. (2006). Care planning in palliative care. In: B. Gates (2006). 'Care planning and delivery in intellectual disability nursing'. Oxford: Blackwell Publ.(pages 195-211).
- Read, S. (2006). Communication in the dying context. In: S. Read (2006) 'Palliative care for people with learning disabilities'. (pp 93-106). London: Quay Books.
- Read, S. & Bowler, C. (2007). Life story work and bereavement: Shared reflections on its usefulness. 'Learning Disability Practice', 10(4), 10-15.
- Read, S. & Thompson-Hill, J. (2008). Palliative care nursing in relation to people with intellectual disabilities. 'British Journal of Nursing', 17(8), 506-510.
- Read, S. (2008). Loss, bereavement, counselling and support: An intellectual disability perspective. 'Grief Matters', 11(2), pp54-59.
- Reynard, C., Clarke, C.L., Gibson, L, and Matthews, D. (2003). Difficulties in identifying distress and its causes in people with severe communication problems. 'International Journal of Palliative Nursing', 9(4), 173-6.
- Reynard, C., Clarke, C.L., Gibson, L, Matthews, D. (2006) Pain and symptom management. In: Read, S. (2006). 'Palliative care for people with learning disabilities'. London: Quay Books. (P:39-57).
- Swinton, J. and Powerie, E. (2004). 'Why are we here? Meeting the spiritual needs of people with learning disabilities'. London: Foundation for People with Learning Disabilities.
- Swinton, J. (2006). Spirituality, suffering and palliative care. In: Read, S. (2006). 'Palliative care for people with learning disabilities'. London: Quay Books. (P:121-135).

- Symonds, D. & Howsam, K. (2004). Breast awareness in learning disabilities. 'Cancer Nursing Practice', 3(1), 8-10.
- Thornton, C. (1996). A focus group enquiry into the perceptions of primary healthcare teams and the provision of healthcare for adults with a learning disability living in the community. 'Journal of Advanced Nursing', 23: 1168-76.
- Todd, S. & Blackman, N. (2005). Reconnecting death and intellectual disability. 'European Journal of Palliative Care', 12 (1), 32-34.
- Todd, S. (2004). Death counts: The challenge of death and dying in learning disability services. 'Learning disability practice', 7(10), 12-15.
- Todd, S. (2006). In: Read, S. (2006). 'Palliative care for people with learning disabilities'. London: Quay Books.
- Tuffrey-Wijne, I. (1997). Palliative care for people with learning disabilities. Nursing Times, 93 (3), 50-51.
- Tuffrey-Wijne, I. (2003). The palliative care needs of people with learning disabilities: A literature review. 'Palliative medicine', 17, 55-62.
- Tuffrey-Wijne, I. & Davies, J. (2006). This is my story: I've got cancer. 'The Veronica Project': an ethnographic study of experiences of people with learning disabilities who have cancer. 'British Journal of Learning Disabilities', 35: 7-11.
- Tuffrey-Wijne, I. (2007). In memoriam: John Davies. 'British Journal of Learning Disabilities', 35(6).
- Tuffrey-Wijne, I., Hogg, J., Curfs, L. (2007). End-of-life care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature. 'Journal of Applied Research in Intellectual Disability', 20:331-344.
- Vanier, T. (1973). 'Nick: Man of the Heart'. In: T. Linehan (1990). Freeing alter egos. 'Care Weekly', August 4: 17.
- World Health Organisation (2003). www.who.int/cancer/palliative/definition/en



An easy read summary of this guide is also available.

If you would like to order an easy read version, or have any questions about this guide, please call 01159 827 022.

Both versions are also available online at
www.mencap.org.uk/endoflifecare



Mencap
123 Golden Lane
London
EC1Y 0RT
Tel: 020 7454 0454
www.mencap.org.uk