# The route to success
in end of life care - achieving quality for people with learning disabilities

# Contents

There are currently approximately 1.5 million people in the UK with a learning disability. People with learning disabilities account for about 2.5% of the English population with an average GP surgery likely to have 50 learning disabled people on its register.[1] Due to improved health and social care the population of people with learning disabilities is expected to rise by 1.1% of its total each year and the numbers of older people with learning disabilities (ie, 60 years plus) is set to increase by 36% between 2001-2021[2] and consequently so too the end of life care needs of this group.[3]

Many learning disabled young people who have life limiting illnesses, and are currently served by children's hospices, are now likely to live to an age where they will require adult end of life care services. So whilst the end of life care needs of people with learning disabilities have until recently been little understood, never has there been a more pressing need for information and good practice models. The aim of this publication is to contribute to that development of thinking and practice.

Photo: Mencap 2011

Learning disability is described as "*a … reduced ability to understand new or complex information, to learn new skills … [and] … to cope independently … which started before adulthood [and which has] a lasting effect on development.*" [4]

The term `learning disability' (often used interchangeably with `learning difficulty') is used to describe a range of disabilities which vary greatly from one person to another and which may be accompanied by physical disabilities. The term `service user' will be used throughout the document as people with learning disabilities are also often recipients of services already.

The impact of a learning disability may differ according to the accompanying life circumstances of the affected individuals. For some people this can mean limited life chances or restricted personal networks and an inability to live independently or to develop valued roles. The difficulty with processing or remembering new information may result in the individual finding it hard to adapt to new situations or people. At the most severe end of the spectrum, it may mean that the person is without speech, has little comprehension and is dependent on carers for all aspects of daily living. While many people with mild learning disabilities may live completely independently and be unknown to services, some of these will be significantly challenged by the issues that arise when confronted by serious illness, death and bereavement.

The healthcare of people with learning disabilities is notoriously difficult; this is partly due to the fact that many people have a number of chronic conditions in addition to their learning disability (see below), but it is also related to how poorly served people with learning disabilities have historically been by mainstream healthcare.[5] This has been highlighted in several reports, most recently Mencap's *Death by indifference* (2007)[6] and the subsequent independent enquiry *Healthcare for all* (Sir J Michael, 2008).[7] Currently a Department of Health funded confidential enquiry into premature deaths of people with learning disabilities is being conducted by the Norah Fry Research Centre. All of these initiatives are aimed at improving the health care (including end of life care) of people with learning disabilities.

The Disability Rights Commission report *Equal treatment: closing the gap* (Part 1,2006)[8] indicated that people with learning disabilities are likely to encounter all of the major life-threatening diseases at least 5-10 years in advance of the general population and survive for much shorter periods than the general population.

**People with a learning disability are more likely than non-learning-disabled people to also experience:**
- Obesity – with consequent implications for both heart disease and diabetes (28.3% of the learning disabled population versus 20.4% of the general population)[9]
- Specific long-term illness or disability (61% versus 31%)[10,11]
- Epilepsy (22% versus 0.75%)[12,13]
- Mental ill health (50% versus 25%)[14]
- Visual impairment (30% of the learning disabled population)[15]
- Hearing impairment (40% of the learning disabled population)[16,17]

- Respiratory disease, which is the leading cause of death for people with a learning disability. Of the general population 15.5% develop respiratory disease and 17% of those die from it. By comparison, 19.8% of people with a learning disability develop the disease but about 50% of these die from it. [18,19,20]

With regard to cancer the suggestion is that it is less prevalent among people with a learning disability (16% versus 26%). Research has found a lower incidence of cancers of the bronchus, prostate and breast. However, the research also found that people with learning disabilities are more at risk of gastric cancers, which account for 58% of cancer deaths in people with learning disabilities but only 25% of cancer deaths in the general population.[21,22]

There are particular issues for people with Down's syndrome who are significantly less likely to develop certain types of tumours (women with Down's syndrome are up to 10-

25 times less likely to develop breast cancer than the general population). However, they are more likely to develop other tumours such as testicular (2-13 times more common), liver (7 times more common) and lymphomas. They are also at greater risk of childhood leukaemias – although they are much more likely to be cured of these because of a genetic mutation that both predisposes them to the leukaemia and enhances the effect of chemotherapy on the disease.[23]

Research has also found that people who have schizophrenia have a 90% increased chance of developing bowel cancer and women with schizophrenia have a 42% increased chance of developing breast cancer.[24] These are important statistics given that people with a learning disability are 3 times more likely to develop schizophrenia.[25,26]

All people with a learning disability are 4 times more likely to develop dementia than the general population, irrespective of the cause of their disability. For people with Down's syndrome there are particular issues. 80% of people with Down's syndrome can now expect to live into their 50s.[27] However, along with an increased lifespan comes an increased likelihood of developing dementia, with 55% incidence in those over the age of 60.[28] Alzheimer's dementia in people with Down's syndrome has a much earlier average onset age of 54 years and an average course of 5 years from diagnosis to death.[29]

Photo: Mencap 2011

The aim of this publication is to provide a practical guide which supports anyone caring for people with learning disabilities to engage with key professionals to ensure that those who may be in the last months of their life receive high quality end of life care. The guide may also be useful to those health or social care professionals who irregularly come into contact with people with learning disabilities in clarifying what measures need to be taken to ensure that they can access appropriate care.

People approaching the end of their life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to giving people the opportunity to have a dignified death and includes offering families, friends, staff and other service users bereavement support following a death.

This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital, in the community or in any other setting. It is intended that the guide will support practitioners and staff (working in all the settings in which people with learning disabilities live) to develop their awareness and understanding of the end of life care pathway and how it relates to people who have learning disabilities.

Photo: Mencap 2011

Network for Palliative Care of People with Learning Disabilities (NNPCPLD))[30] alongside a range of organisations and professionals who work with people who have learning disabilities in health or end of life care. In addition, the development of the thinking for this publication has been supported by the GOLD (Growing Older with Learning Disabilities) programme, which is a facilitated group of older people with learning disabilities who together have been considering the issues of ageing, illness, death and bereavement over the last decade, sharing their experiences and insights to good effect with professionals and researchers. An easy read version of the consultations with the GOLD group will be developed to supplement this professionals' guide with the aim of enabling people with learning disabilities themselves to engage with, and contribute to, development of thought in this area of practice.

## Core principles for delivery of end of life care

- Care is client-centred and integrated
- Treat individuals with dignity and respect
- Identify and respect people's preferences
- Provide care after death.

Consequently, the guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death. Each section outlines the relevant step of the pathway and highlights issues to consider about the individual's care and the practitioner's role in that care. We also include case studies highlighting best practice. It is recognised that sometimes the person's current living situation will not be suitable to provide end of life care and therefore this guide also seeks to support these situations by addressing how to signpost on effectively to more appropriate resources.

This guide has been developed by the National End of Life Care Programme (NEoLCP) as part of its route to success series. The work has been undertaken in conjunction with the PCPLD Network (formerly the National

## Key considerations

- As a result of the challenges presented to mainstream health and social care services by the needs of people with learning disabilities, the diagnosis of life-threatening illness often occurs late. Unless service settings have given thought in advance to the likely issues this may present, the diagnosis will present as a crisis which can only be resolved by timely, efficient team working across all service settings

- Historically people with learning disabilities have lived in contexts (both professional and family) where it has been considered not to be in their best interests to tell them about serious illness or death. Whilst it is now understood that this is unhelpful there is still a great deal of resistance to sharing the taboo subjects of death and dying with people who have learning disabilities; this will have implications for good end of life and bereavement care

- Whilst learning disability services advocate personal autonomy for service users, many people with learning disabilities will not have extensive experience of making choices or controlling their own lives. This will need to be borne in mind in any end of life care planning and will inevitably slow the process; supporters will need to be committed to 'taking as long as it takes' to ensure individuals understand the implications of any information and the consequent decisions that need to be made

- Where service users live in their own homes or under the care of third sector organisations then staff may not be trained in physical health care or care of the dying and may not see provision of end of life care as part of their role

- The setting in which the person with a learning disability lives will have a bearing on how their end of life care may be provided. Where the person lives alongside other service users, early negotiation will be required to ensure their ability to remain in their own home until their death, should this be their wish to do so

- Many hospitals and hospices do not have experience of caring for people with learning disabilities who are dying. Learning disability organisations, hospitals and hospices need to seek educational opportunities to ensure they are fit for purpose to care for this client group at the end of their lives

- Previous bad experience of mainstream health and social care may make service users reticent to engage with those organisations which are proficient in care of the dying

- Where the dying person with learning disabilities has challenging behaviour, mental health problems or profound learning disabilities then careful consideration needs to be given to the best place in which to provide their care and to the support needs of those around them

- Much of the expression of illness or distress will be made behaviourally by the person with a learning disability. Therefore mainstream health, social care and end of life care staff will require the support of their learning disability colleagues to enable them to understand what is being communicated and how best to respond to it.

It is difficult to predict when people are approaching the last 6-12 months of their life, and this may be particularly so in the case of people with learning disabilities, but there are some ways to work with health colleagues to improve recognition and consideration of the important issues that should be addressed at this time.

Providing effective, high-quality care for someone during the end of their life is a highly skilled role and a challenging one. Without support and information, staff and carers can find the experience overwhelming.

Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone. If it is not clear how long this person is likely to survive, then it may be advisable to err on the side of caution and to begin end of life care planning (advance care planning[31]) at the earliest possible opportunity so that it can be undertaken at the emotional and cognitive pace of the person. Best practice would suggest that this should be an activity which is integrated into the essential life planning[32] of all service users and reviewed at each new stage of the person's life or move of services. In the case of the terminally ill person obviously this will be limited to some extent by the service user's understanding of their diagnosis and prognosis, as well as that of friends and family members. However, a proactively open attitude to discussions about end of life decision making may mitigate this.

Where the person has little or no understanding of their situation, or where their mental capacity is in question, then early discussions within the team will be necessary to guarantee processes are established to ensure the person's best interests are served in
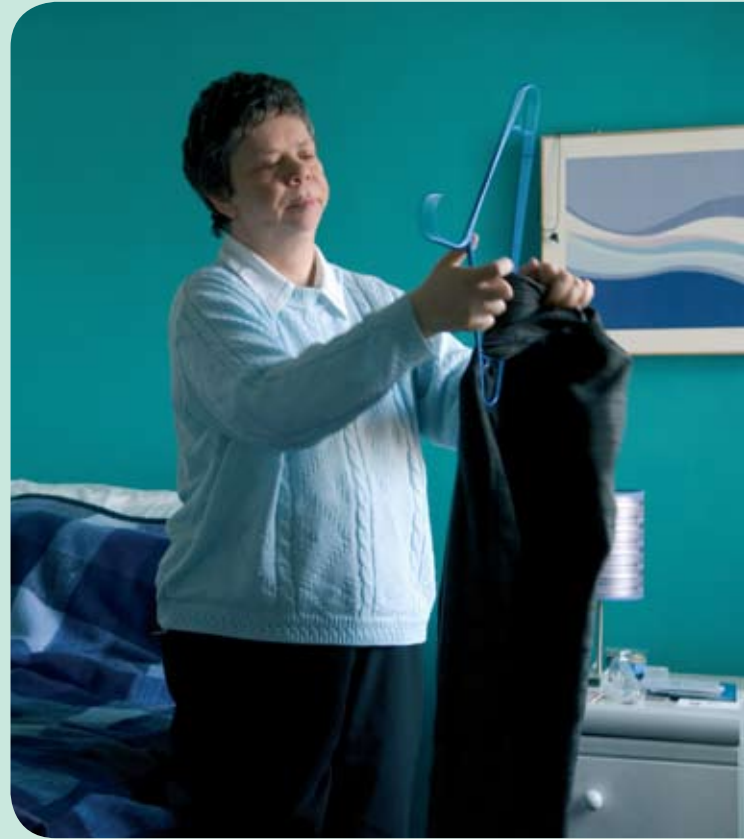
Photo: Mencap 2011

a timely manner.[33] An early referral to end of life care staff may also be advisable for whilst the person may not currently have specialist needs it is likely that the complexity of their living situation, communication needs and social networks may mean that it will take longer than normal to get to know the person and understand their needs and those of the people closest to them. It may be that on initial referral no specific action is taken but the service user's future support needs and wishes may be identified, and their illness progression can be monitored and reviewed when appropriate.

Communication needs are often of primary concern where the person has a learning disability (whether they use spoken language or not) and this is particularly so with regard to

symptom assessment and treatment. Given the relative areas of expertise, it will be important to develop early relationships between all staff involved in the end of life care of the service user to ensure that by working collaboratively the person's needs are best understood and met. Tools such as the Disability Distress Assessment Tool (DisDAT)[34] are a useful way for those who have most knowledge of the person to work alongside those who are expert in symptom control to make sure that the person's needs for symptom control are effectively met, leaving them free to consider the other non-physical elements of the progression of their illness.

While the primary contribution of the palliative care team will be around symptom assessment and management it should be remembered that they have much to contribute with regard to communicating bad or complex news and dealing with spiritual and psychological

aspects of end of life care. Learning disability staff can help the palliative care team to work most effectively by enabling them to understand the social, emotional, spiritual and psychological worlds of the person. Palliative care staff can support those closest to the person who is dying by enabling them to 'read the road ahead' in considering what are likely to be the issues as the disease progresses. As they move towards death, they can be especially helpful in helping non-health staff to recognise the physical symptoms which would suggest that the person is moving towards death and the preparations required for the person and their loved ones at this time.

This resource pack is intended to help you deal with the challenges of supporting someone who is dying and identify how and when you need to access specialist support from health professionals and other organisations.
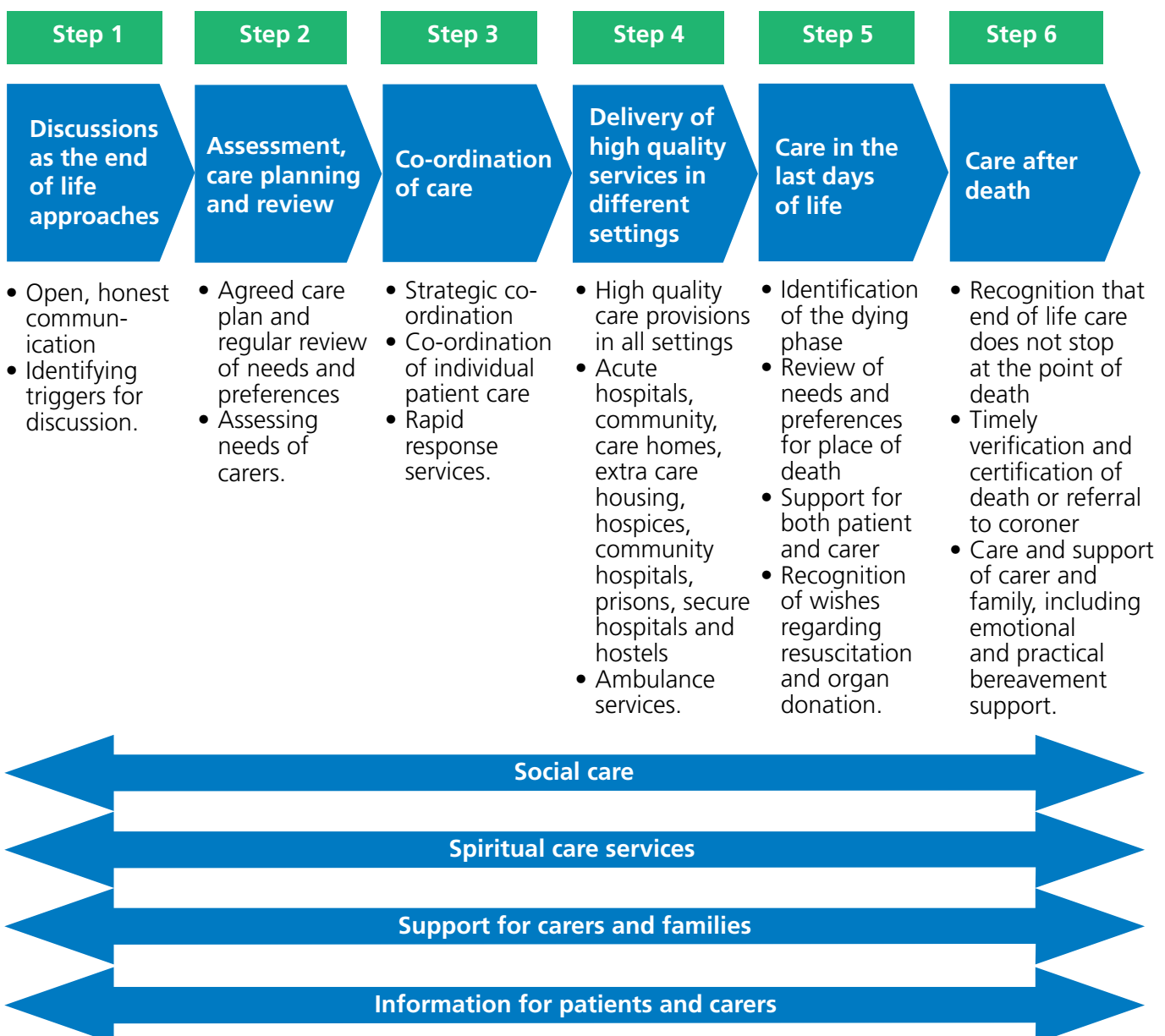


Photo: The GOLD group

# End of life care pathway

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death.

Each section outlines the relevant step of the pathway and issues to consider about the individual's care and the practitioner's role in that care. (Reference can also be made to the appropriate quality marker for end of life care. See appendix 1 for full list.) We also include case studies highlighting best practice.

**The guide will reflect the need to work with other professionals in health and social care and assist anyone working with people with learning disabilities to:**
- Identify approaching the end of life phase
- Review care planning
- Help to review practice
- Support communication and team working (including family carers and friends)
- Understand that staff and fellow service users may be affected by the death of a client and identify some measures to support and provide information.

| Step 1 | Step 2 | Step 3 | Step 4 | Step 5 | Step 6 |
|---|---|---|---|---|---|
| **Discussions as the end of life approaches** | **Assessment, care planning and review** | **Co-ordination of care** | **Delivery of high quality services in different settings** | **Care in the last days of life** | **Care after death** |
| • Open, honest communication<br>• Identifying triggers for discussion. | • Agreed care plan and regular review of needs and preferences<br>• Assessing needs of carers. | • Strategic co-ordination<br>• Co-ordination of individual patient care<br>• Rapid response services. | • High quality care provisions in all settings<br>• Acute hospitals, community, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals and hostels<br>• Ambulance services. | • Identification of the dying phase<br>• Review of needs and preferences for place of death<br>• Support for both patient and carer<br>• Recognition of wishes regarding resuscitation and organ donation. | • Recognition that end of life care does not stop at the point of death<br>• Timely verification and certification of death or referral to coroner<br>• Care and support of carer and family, including emotional and practical bereavement support. |

**Social care**

**Spiritual care services**

**Support for carers and families**

**Information for patients and carers**

*"We don't always talk about cancer and dying when we meet. Mr H said that he didn't mind us visiting but didn't want to talk about sad things all of the time, so we agreed that we would only talk about them sometimes and I would always check if it was okay"* Palliative care social worker

Identifying when people are approaching the end of their life can be very complex. In the case of people with learning disabilities the late presentation of serious illness, limited verbal communication and service settings which are not used to dealing with physical ill health can all exacerbate this. To ensure that people with learning disabilities get the best end of life care possible it is important to develop partnerships across all settings with both formal and family carers.

One of the key challenges for staff and family members is to know how to develop sensitive, open conversations with people with learning disabilities who are nearing the end of life. These conversations need to take account of the person's preferred communication style, their cognitive abilities, their understanding of language, serious illness, death and dying as well as their concept of time.

Photo: Mencap 2011

## Issues to consider

- How do you identify service users who are approaching the end of life?
- How do you then also identify which service users who are approaching the end of life also have a learning disability?
- Does the service user have a personal communication passport?[35] Does it include information concerning their preferred communication style and needs and their current illness?
- What things or circumstances might indicate that it is an appropriate time to begin a discussion on end of life care?
- Is there organisational agreement about who should initiate or take responsibility for ensuring conversations about end of life are held? Do you have appropriate accessible resources (eg, pictorial/visual information) to support these conversations?
- Where the service user does not have capacity for an advance care planning conversation who else should the conversation be held with and who needs to be involved?
- What are the options for future care for this person and to what other services may referral be necessary to ensure their best interests are served? Is there an established referral pathway to these services?
- What support might mainstream health, social or palliative care services require to enable them to adapt to provide appropriate end of life care for this person (eg, training in knowledge of learning disability, or education regarding the importance of non-verbal communication or in the use of DisDAT)?

## Your role

- Use appropriate tools such as DisDAT[36] to monitor any increase in the service user's symptoms or to determine a change in their condition – seek the advice of palliative care specialists where appropriate
- Ask yourself the question "Would I be surprised if this person were to die at some stage in the near future; ie, within the next six months to a year?"
- Given the person's understanding of illness, their concept of time and their communication style, consider carefully whether and when it is appropriate to open a supportive discussion about their wishes for the end of life
- Remember that even people with a mild learning disability may understand language in a literal, non-euphemistic manner and therefore anything that is communicated should take account of this. For instance, avoid the use of abstract language in discussions about end of life (eg, talk about 'dying' rather than 'passing away').[37,38]

### Your role continued

- As the person's ability to concentrate may be impaired it is better to have a number of short, single-focus conversations than to try to communicate everything in one session. If your role cannot accommodate this, it is important to delegate the task to someone who can give the time needed to help the person understand
- Family members may need support to overcome their natural instinct to 'protect' their loved one (whether the person or another family member) from the knowledge of the diagnosis or prognosis. It will be important to work within mental capacity legislation: to assert the rights of the individual to make important decisions whilst expressing empathy and understanding for the concerns of the family[39]
- Take into account the environment in which discussions about end of life care are to be held. Remember that, for example, for those learning disabled service users who also have an autistic spectrum disorder environments which are noisy, very bright or have strong smells associated with them may initiate a sensory overload which can impede their ability to understand the information being imparted. For some service users, previous traumatic experience of healthcare may make them nervous of staff in uniforms or of certain procedures; eg, those involving needles
- Begin to record expressed end of life care wishes in accessible formats to be kept in an agreed place (eg, within the service user's bedroom). Ensure all staff and other key people (eg, family members) are aware of its location
- Ensure that service users approaching the end of life are on an end of life supportive care register (eg, the Gold Standards Framework register[40]) and are reviewed regularly

- Ensure that service users who have a learning disability have regular access to all those professions and services required to meet the range of their end of life care needs – it is likely that this will include both learning disability and palliative care staff
- Consider who else within the person's circle of relationships might require support to understand the implications of the person's illness and their need for additional care and who might best provide this for them.



Photo: Mencap 2011

### Top tips

- Remember that the global label `learning disability' is unlikely to tell you much about the specific needs of the individual service user. They will require a full, multi-professional assessment which takes account not only of their cognitive abilities but also of their previous experience of serious illness, death and bereavement, and their coping styles, strengths and capabilities. Drawing on person centred planning models may help with this[41]

- Opportunities to discuss death and dying in non-threatening ways should be developed (eg in response to television programmes or newspaper stories). Service users with a learning disability should be encouraged and supported to express their opinions on these issues as on any other topic but it must be remembered that many people will not have a full understanding of the concepts surrounding death and bereavement or may (because of previous experience) find such discussions distressing

- Consider how such conversations might be integrated into documentation which arises from activities such as the development of life plans or life story books[42]

- Where the service user does not have a will or a statement of wishes and preferences then consideration should be given as to whether it would be in their best interests to develop one. As this is likely to take longer to develop than for someone without a learning disability it is important to begin thinking about this at an early stage of a life-limiting illness[43]

- Where service users have limited verbal speech (or where their verbal skills seem to outweigh their comprehension)

a speech and language therapist, psychologist or other dedicated member of staff should be deployed to facilitate the expression of the service users end of life care preferences at whatever level they are able to conceive of them

- Staff or family members close to the person with a learning disability may find it too distressing to talk to the person about their illness; palliative care staff may be well placed to do this but may not have the requisite communication skills. Therefore, good partnerships need to be forged to support the service user at all stages of their illness and dying

- Advocates are a good source of support throughout the progression of the illness and therefore both learning disability and palliative care services should make proactive partnerships with advocacy organisations. It may be necessary to involve an independent mental capacity advocate (IMCA)[44] in the decision making process for some individuals

- Identify training in your area to support the development of good end of life care for people with learning disabilities.

## Case study

We learnt a lot from being part of the care and support team for two people with learning disabilities, which encouraged us to get together with local colleagues in the field of learning disability. What we realised is how vulnerable people with learning disabilities are to not getting best care because people are cautious about getting health services like hospices/community palliative care in to help, especially if there is uncertainty around what people know of their diagnosis/their situation. We also learnt that often key carers don't know the health system and don't then know what is available and what to expect from healthcare; for example, when hospitals can be really helpful and offer good treatments, and when hospitals cannot offer any more treatment (ie, when there are important choices to be made about care), and when its best to have more care at home.

We would now much rather be involved early, for an early hello and a talk through anything which worries or concerns either the individual with the illness or their carers/family/key friends. And we have learnt that face-to-face meeting means so much and is much more productive in identifying and understanding worries than a telephone call.

We may stay involved to build up relationships and confidence, or we may be there as a resource to be called on in difficult times (everyone is different and needs different approaches). But that early meet means that when someone is becoming more poorly we can be quickly there again to help and advise both the person who is now poorly and those who are helping look after them. We have learnt that it is really important to know about the poorly person as a whole person not just a poorly person - to understand who their friends and key supports are, their likes and dislikes, how they express worries or symptoms such as being uncomfortable, and so on, so that we can be helpful. And when people are actively dying we are really familiar with the comfort and care issues for someone

dying, and the need to support all around them, and like many palliative care services can offer hands on care to help those caring both as friends/family and as professional carers.

As a result of our experiences we changed our referral form so that any referrer could write about additional potential vulnerabilities such as having a learning disability. We changed the way we process referrals to make sure that if someone does have learning disabilities then we quickly identify and talk with their key support and learn things like how they express themselves and what the main issues are at the moment. And we ensure that one of our team meets with the poorly person and their key support early. This way we have been much more helpful in supporting care, and we have gradually got to help care for more people with learning disabilities who have complex advanced illness, through difficult times and in between, and in care of the dying. People locally have got to know that there is help out there, thanks to our local learning disability nurse colleagues, and they know where to go now to get useful support. Our staff are now more confident working with and understanding people with learning disabilities too. So that getting to know and continuing to meet with our local learning disability colleagues, encouragement of earlier referrals and early meets with people with advanced illness have been helpful all round.

Corinna Midgley, medical director, Saint Francis Hospice

*"Person centred planning gave an insight into V as a person, showed how to support her and let her make her choices before she dies. Just because someone is dying they should not be treated differently; knowing how the person is normally and what's important to them are really important. It will be good to put things into practice and how best to support her to help keep her comfortable and to give her a good death."* Feedback from Dorothy House hospice end of life person centred planning day

An early assessment of a service user's needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as identifying any area of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each individual.

### Issues to consider

- Does your care plan assessment take into account all aspects of end of life care (social, emotional and spiritual) as well as physical?
- Is there any means by which the person's physical and emotional distress is assessed and recorded; eg, DisDAT? Has this documentation already been completed and is it accessible to all those involved in the person's care? Is it reviewed regularly, not just in times of crisis?
- Are all those involved in the assessment and delivery of care confident of their ability to understand and meet the needs of a person with a learning disability throughout the progression of their illness? Are there identified sources of training and/or supervision for the whole extended team on this?
- Has the service user's 'circle of support' been identified and are the roles of all those involved clear? Is there adequate support for all those (both family and professional carers) to carry out their roles, remembering that some of them may also have a learning disability?

### Your role

- Consider what impact a learning disability may have upon the expression of end of life care choices and how you can work with others to ensure a holistic assessment of these
- Assess and respond sensitively to the social, psychological and spiritual needs and wishes of service users
- Where necessary, support the assessment of an individual's ability to make decisions about their care, involving additional professionals (eg, learning disability nurse, psychologist, speech and language therapist) and advocates as appropriate
- Work with others to identify, record and respond to an individual's personal wishes and preferences about their future care and implement regular reviews verifying this with their local GP if necessary[45]
- Documentation of the advance care planning process and significant decisions (eg, advance decision to refuse treatment including DNACPR decision if the individual has capacity to make a decision with regard to resuscitation[46]) should be in an accessible format which is held by the person or in a secure place that they agree to[47]
- With the service user's permission ensure that information about personal wishes and preferences is communicated to all relevant people across whichever settings the person accesses care (including health, social care, supported housing, GP and out-of-hours services).

Photo: Mencap 2011

**Top tips**

- In residential, nursing, supported housing or day care settings, service users can be helped proactively to understand the issues related to expression of preferences about end of life care choices, perhaps through facilitated group discussions or the life-planning process
- Learning disabled service users who have specialist palliative care needs should have these met by the local palliative care team (based in the community, hospice or hospital). Palliative care service users who have a learning disability are likely to require the support of local learning disability services in addition to the palliative care team. Both services should seek the support and expertise of the other to ensure the end of life care needs of the person with a learning disability are most adequately met
- Person centred planning approaches drawn from learning disability services may offer useful strategies and tools for developing an individualised, holistic end of life care plan[48]
- In a person with a learning disability, distress and physical pain may be expressed behaviourally rather than reported verbally, even if the person normally uses verbal speech to communicate. Consequently, a team approach is essential in determining the meaning of such expression; tools such as the DisDAT can help with this process
- People with learning disabilities are likely to have the same range of opinions regarding treatment decisions and end of life care options as the general public. Assumptions should not be made as to what these are likely to be but, rather, timely, sensitive and consistent support should be given to service users to consider their options and to help them to express these in the formats required by professionals responsible for making them happen
- Where written confirmation is usually required for a decision (eg, advance decision to refuse treatment) legal advice and support should be sought at an early stage and other forms of confirmation (eg, audio recordings) should be appropriately developed[49]
- Identification of who the service user considers to be the person they wish to act on their behalf needs to be undertaken at an early stage. The nominated person may not be the biological next of kin and may be someone with a learning disability. Advice may need to be sought as to how to ensure the service user's wishes are honoured whilst behaving appropriately within legislative and organisational frameworks
- It is important for all those involved in the care of the service user to 'read the road ahead' in terms of determining likely issues with regard to future care or placement. Everyone involved should have the opportunity to raise issues of concern, whether these are practical or emotional, in order for solutions to be developed. A team approach which includes the service user, their family and friends as well as professionals is likely to result in the most robust advance care plan, though skilled facilitation of this is likely to be needed.

**Case study**

Johnny, a 62 year old man with a mild learning disability, was referred to the community palliative care team linked to his local hospice. He had been diagnosed with a cancer which had spread to his liver and so he was considered to be in need of end of life care. However, after assessment and treatment of his symptoms by the palliative care nurse specialist, he was considered not imminently dying and was instead referred for support from the palliative care social worker.

After a stay in hospital three years ago, Johnny had been inappropriately placed in the dementia unit of a nursing home; consequently, much of his current misery was related to his care setting rather than his cancer diagnosis. He said that he wanted to move out because he couldn't talk to any of the other residents because they weren't well and that the staff didn't take him out anywhere and that he wanted to live in his own flat again. Sadly, his own flat, which was

in the area which he had grown up in and had happy memories of, had already been given up. The current situation was clearly not amenable to helping Johnny to come to terms with his diagnosis or to be able to begin to consider the issues that were likely to arise in the future. The first task of the palliative care social worker, therefore, was to address Johnny's housing needs; eight weeks later he was transferred into a younger person's nursing home where his current mobility and continence needs could be met and where he would be able to stay as his condition progressed.

Although happy to engage on the issues of housing Johnny initially was not keen to discuss the topic of his diagnosis. He understood, however, that the social worker came from a hospice, and he understood the nature of hospice care having had friends die there. The social worker therefore spent time with him talking about his life rather than focusing on his death. Johnny chose to share his photo album with the social worker

and this allowed him to find out more about whether Johnny had any living family members or friends. In the event, although Johnny did have siblings he had not seen them for many years. With the help of the social worker Johnny was able to trace his missing relatives and renewed contact with them, seeing one of them regularly from then on.

In time, Johnny was able to speak about his cancer: he was able to say where it was in his body and even to point to the physical location. On referral Johnny had been described as "non-compliant" and therefore was not having any chemotherapy. Mindful of this, the social worker asked why he had refused chemotherapy and Johnny said that he didn't want to be in pain and lose his hair. Exploring further whether Johnny knew the implications of this decision he said that he knew he might get "more sick". The social worker suggested a joint visit with the palliative nurse specialist so that Johnny could ask her medical questions and they together could help him plan and make decisions.

On the joint visit, a lengthy discussion was undertaken which involved the social worker asking Johnny if he could ask a particular question and him either saying yes or no. Throughout the discussion Johnny looked mainly at the social worker and the social worker looked at the nurse when he asked the questions. This seemed to work. The conversation covered cancer, chemotherapy and side effects, and the pros and cons of treatment. Simple jargon-free language was used, and if the nurse used a term that Johnny did not understand then the social worker asked what it meant. During the conversation, Johnny's fear of hospitals and especially of the oncology clinic was discussed. Johnny described feeling frightened every time he went to see the oncologist because of what they might say and that they might use the word cancer again. He also said that he didn't understand much of what they were talking about and he felt that they didn't care about him. This perhaps explained why all letters by every consultant and doctor he met referred to Johnny as aggressive and hostile.

Over 3–4 months, the social worker met regularly with Johnny involving the palliative care nurse when necessary. Latterly they had to explain to him that his condition had progressed, that there was no more treatment that he could have to help and that his lifespan was now short. Conversations after this focused on the future, about advance care planning and making a will. He has been very specific about the two charities he wants to leave his money to.

*"I really dislike the term `carer' most people when they hear it think of people caring for someone with cancer for six months or two years. Try providing care for forty years non-stop; then talk about being a carer."* Family carer of an adult with learning disabilities

Once a care plan has been agreed it is important that the services needed are effectively co-ordinated, this can be particularly complex in the case of people with learning disabilities who may have a number of health, social care and third sector agencies involved in their lives. It is therefore vital at an early stage to establish good systems for communication and appropriate transfer of information across settings in keeping with the service user's wishes.

As the service user's condition deteriorates there is need for a regular review of communication and team working and a willingness for different members of the team to take the lead (or become the key worker) as best befits the needs of the person. This means that at times it will be most appropriate for this to be a member of learning disability staff but at others (perhaps in the later stages of an illness), for a member of palliative care staff to take on this role. Carers are a key component of any team and consideration needs to be given to the needs of family carers (who in the case of someone with a learning disability may have been carers for decades) and to the needs of those carers who also have a learning disability.[50]

Photo: Mencap 2011

Photo: Mencap 2011

## Issues to consider

- Is there a communication system in place to keep everyone involved in the care of the person with a learning disability informed of the evolving end of life care plan?
- Has a key worker been identified for the person so that there is a lead person not only for the co-ordination of all services and care but who also has a responsibility for keeping family carers and friends up-to-date with the emerging situation in keeping with the person's wishes?
- Are systems in place for services to respond rapidly and appropriately (out-of-hours as well as during working hours) to changes in circumstances as end of life approaches (eg, changes in medication or equipment)? Are these services aware that the person has a learning disability and of any specific needs (eg, regarding communication) which they have as a result?
- Where there are issues related to mental capacity and decision making, is there an established best interest process which is reviewed regularly and which takes into account both the person's wishes and the wishes of those closest to them?

## Your role

- Ensure that local healthcare professionals are aware of those approaching the end of life. Where there are mainstream systems in place to ensure consistent, high quality end of life care (eg, end of life care register), ensure that the person is included within these
- Make sure that you know who your key contacts are across the provider services, voluntary bodies and social care sectors
- Make sure that good communication systems are in place with all relevant services and with family carers and friends
- Understand when there is a need to formally review consideration of the best interests of the service user, and ensure that the appropriate meetings take place to make this happen involving the service user, their family carers and other loved ones
- Try to ensure that individuals have the benefits and services they are entitled to. These can be claimed under special rules when someone is approaching end of life. A doctor has to sign a special form to initiate this process (DS1500)
- Inform out-of-hours services of anticipated care needs
- Help the service user and those closest to them to develop good communication services with out-of-hours services. Eg, identify a key person/number that can be fast dialled to get the help that is required in the night or at weekends
- Inform the ambulance service of anticipated care needs and how these are likely to be expressed by someone with a learning disability.

**Top tips**

- Find out which pharmacies your local hospice uses. These are more likely to offer out-of-hours delivery of drugs
- Build strong relationships with other services to help you provide good end of life care; for instance, GPs, palliative care teams and social care services.

**Case study**

Angela, who had mild learning disabilities, was in her mid 80s when she was diagnosed as having advanced oesophageal cancer and being in need of palliative care. Living in a small group home, where she had been for many years, her carers wanted to enable Angela to spend her final days surrounded by friends. However, they were anxious that as a team they could not provide all of the care Angela would need and in particular Angela's end of life care. The Macmillan nurse made some initial visits to the home and facilitated the staff group's information and support needs enabling them to be clear about how best to support Angela and what the likely progression of her illness would be.

As this was a rural setting Angela had to travel 30 miles for her hospital visits which was particularly difficult during the winter months and also meant that any hospital admission left her isolated as her friends were not able to travel that distance independently to visit her. The Macmillan nurse arranged with the local cottage hospital, district nurse and GP for Angela to be placed on a nurse-led admission pathway so that any need for medical or nursing support could be met at the local cottage hospital.

In the last months of Angela's life the Macmillan nurse co-ordinated Angela's care with the home carers, GP, district nurse and hospital team. This enabled Angela to spend the majority of her time at home. In the last days of her life she was admitted to the cottage hospital where her friends were able to visit daily and the home staff were able to continue to provide care for her whilst being reassured that her night-time and more complex care needs were taken care of. Angela died contentedly in this setting having had high quality palliative care from the network of specialist and generalist carers needed to meet her needs. Regular contact with friends and those who were most important to Angela was also enabled.

# Delivery of high quality care in the settings in which people with learning disabilities live

On being told that she was to be discharged from hospital to a nursing home; a 64 year old lady with learning disabilities said *"I can't go to a nursing home; I'm married. What's the point of me being married and living in a home and him living somewhere else?"* When the nursing and medical staff left, she turned to the palliative care social worker and asked *"Do I have to go?"*

In the last year of life, service users and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of where they are being looked after. A number of people with learning disabilities will be significantly younger than the general population of dying people and may have multiple long-term physical and psychological problems which may make their care and access to appropriate end of life care placements complex.

For some learning disabled people, living in their own home will have been a great achievement and they will naturally want to stay there irrespective of the inadequacies of their care package. Therefore the care team will need to be cognisant of this in balancing assessments of `risk' alongside a need to fulfil, wherever possible, the last wishes of the dying person.

Photo: Mencap 2011

### Issues to consider

- Has a policy for the management of end of life care been developed within your organisation? For instance is there a policy for what to do if a crisis occurs at the weekend or in the middle of the night?
- Is there access to training for learning disability staff on end of life care and for end of life care staff on learning disability?
- Does the environment within which the service user lives offer privacy, dignity and respect for individuals, their families and friends as end of life approaches, or can it be adapted to do so?
- Should the care needs of the individual become too complex to be managed in their current setting is there a plan for where the person may be referred to for end of life care?
- What systems are in place to monitor and evaluate the quality and delivery of end of life care?

### Your role

- Develop or be aware of the operational policy for implementing end of life care in your setting
- Ensure that you have awareness and understanding of the core principles and values of good end of life care and how these apply to service users who have learning disabilities
- Promote or participate in the different aspects of end of life care training or training in learning disability which may be available to you
- Where possible, access training around communication skills, assessment and care planning, the *Mental Capacity Act 2005*, advance care planning, symptom management, comfort and well-being
- Give consideration to the environment in which end of life care and support will be delivered – is it appropriate to meet the needs of the individual, their family and other loved ones?
- Use the experiences of relatives, staff or advocates to help provide constructive feedback to support continuous practice improvement.

Photo: Mencap 2011

## Top tips

- Don't forget the role that other service users who have a close relationship with the person who is dying may play in delivering their end of life care. As the individual's condition deteriorates they may require support to continue to play an active part in the care. As this will positively influence their bereavement experience they should be helped wherever possible to do so
- Don't automatically defer to biological relatives in preference to the person who has been nominated by the dying person to express their wishes. This is especially important when the nominated person has a learning disability as they may require the advocacy of staff to ensure their voice is appropriately heard. Even where there is no nominated person, remember to include people closest to the dying person in decision making irrespective of whether they have a learning disability or not
- Staff training needs to include not only the physical aspects of care but also psychological and spiritual care and an awareness of how these concepts may be best applied for people with learning disabilities
- Try to help the individual maintain the maximum level of independence, choice and control for as long as possible
- Work with colleagues across settings to `read the road ahead' with regard to the likely progression of the individual's disease and care needs; begin to develop a readily accessible list of contact details
- Investigate adapted formats of end of life care tools and documentation such as Gold Standards Framework (GSF) or preferred priorities for care (PPC) and determine whether they would be useful in your care setting or in which ways they require further adaptation.



## Case study

Heatherstones is an 8-bedded nursing home for adults with learning disabilities where there is a strong focus on professional development and all members of the team are provided with regular training in order to best meet the changing needs of our clients.

Patsy, who had Down's Syndrome, had lived at Heatherstones for 8 years and was 62 years old when she developed Alzheimer's disease. Initially she was an outgoing, independent lady who was full of life but gradually she lost many of her skills and became more dependent on the staff supporting her. Throughout this time, Patsy's sister Margaret was a strong presence in her life and took an active role in advocating for the care and support she received. It was Margaret who first brought the Gold Standards Framework (GSF) to our attention; she thought Patsy might benefit from it, as well as the other clients living at the home.

In order to fulfil the GSF requirements we had to complete a comprehensive training programme, attend workshops and focus on the palliative care of our clients. The GSF

helped us to identify Patsy's palliative care requirements, assess her needs, symptoms and preferences, and plan her care. The prognostic indicator guide and coding register helped us to plan her care in various stages: the final years, months, weeks and days of life.

Patsy showed a quite gradual decline but as she began to deteriorate a multi-disciplinary meeting was held with her GP, sister, named nurse and the home manager. An advance care plan was put in place detailing her, her family's and her carers' wishes. We agreed that it was in her best interests to be cared for in the familiar surroundings of Heatherstones, surrounded by those she knew and loved. Anticipatory medication was put in place to meet her needs for symptom control and pain management. Our practice was guided by a maxim used frequently in GSF: "to expect the worst but hope for the best."

A few months later, when Patsy became distressed, the GP and district nursing team were called to set up a syringe driver to provide the necessary drugs to maintain her comfort and ensure she was pain free. Due to the anticipatory medication already in place this was done considerably more quickly and easily than would have otherwise been the case and prevented unnecessary distress for Patsy and her loved ones. At this stage it was clear that Patsy had entered the last weeks of life and life sustaining treatments such as fresubin were no longer given. Her family were immediately informed and maintained a regular and welcome presence by her bedside. The district nursing team made twice daily visits to the home to ensure she was given adequate medication to relieve her symptoms and the GP also maintained regular contact. In line with Patsy's advance care plan a decision was made not to admit her to hospital or to resuscitate her if her heart failed.

One of the most rewarding aspects of supporting Patsy was being able to provide an environment where her relatives felt comfortable to spend time with her and give the support and care that she needed, and that meant something to her. Margaret was with her for much of the time during the last week of her life, on occasion spending the night in her room in an easy chair. It gave her an important role where she felt she could provide practical support (helping with personal care) as well as emotional support. Patsy's elderly father was also able to visit and spend time with her, as well as her brothers and nieces and their young families. The local priest was a regular visitor and was able to read her the sacraments of the sick and, when the time came, the last rites.

It was a very precious time for Patsy and her family. Margaret often commented that in her final week Patsy looked more relaxed and peaceful than she had seen her for a long time. When Patsy died, we respected the family's wish that she should remain at Heatherstones overnight so she would not be alone. Her funeral was a fitting tribute to a full and happy life which reached a dignified and peaceful conclusion.

Gerard Wainwright, nursing home manager, Heatherstones

*"Far from being a sombre time, Patsy's last week was full of happy memories. In line with her advance care plan she had her favourite Irish music playing on the stereo and her family showed a number of videos of her at dances, weddings and other happy family occasions. At their request there was lots of laughter during this time, as well as tears and reminiscences about her life."*

There comes a point at which the person enters the dying phase of their illness. In the case of people with learning disabilities this often appears to happen suddenly with little warning, but for many others it can be a gradual process and therefore regular review (by the extended team) is crucial to determine when the individual has entered this phase.

Recognition of the dying phase is very important so that appropriate actions can be undertaken to ensure this process is well supported for the individual, family, friends and staff. How someone dies remains a lasting memory for the individual's relatives and friends and the care staff involved – it can impact greatly (both positively and negatively) on their bereavement experience as well as on how able staff are to continue to do their job in the future.



Photo: Mencap 2011

## Issues to consider

- Are you aware of the changes which may occur in an individual's condition during the dying phase and how best to respond to these?[51,52] Does your organisation have a system in place for advice and to support you with this?
- Are systems in place for involving family, friends and fellow service users in aspects of caregiving or in discussions as death approaches?
- Are you aware of staff preferences regarding their level of involvement in this stage of the individual's illness – be aware that this might be influenced by recent personal bereavement or lack of experience of caring for people at the end of life?
- Has the individual indicated any specific wishes or preferences for this time? For instance, has a preferred priorities for care (PPC)[53] been completed?
- Has an adapted version of the Liverpool Care Pathway (LCP)[54] or other equivalent pathway been implemented? Has the significance of this been communicated to those closest to the dying person?
- Have you responded to any particular spiritual or cultural needs that have been recorded as part of end of life care planning?

## Your role

- Be aware of the processes which occur during the last days of life and be alert to the possibility that on occasions an individual's condition may improve
- Have open, supportive discussions with relatives, friends and other members of staff to ensure you all know what to expect during the last days of life and offer support where needed
- Where possible, adhere to an individual's stated wishes and preferences but remember to check whether they continue to hold the same views as their illness progresses
- If an individual lacks mental capacity, try to identify what they would take into account if they could make their own decisions and incorporate this into any best interest processes
- Where possible have anticipatory prescribing systems in place or a system for rapid access to necessary medication
- Anticipate and be prepared for any specific religious, spiritual or cultural requests an individual may make.



Photo: Mencap 2011

**Case study**

Dorothy House hospice in Winsley, Bradford on Avon has been committed to improving access to end of life care services for people with learning disabilities over a number of years. A couple of years ago they developed a practice facilitator post to ensure good end of life education and care planning across the person's journey.

As well as running a range of training courses for all levels of health, social care and third sector staff, the post holder (DH) has helped individual organisations to plan for their service users' end of life care.

DH has combined the person centred planning model (which is very familiar to learning disability staff) with the range of end of life care pathways and advance care planning tools (familiar to palliative care staff) to ensure that the planning is unique to that individual.

At the heart of this approach is a concern to ensure that what is important *for* the person is combined with what is important *to* the person. Thus all elements of professional duty of care are fulfilled within legislative and organisational frameworks but are married alongside an approach which gives primacy to the expressed wishes of the service user for their end of life care. By facilitating this process, not only is the service user supported to achieve what they want at the end of their life but staff (from all settings) are also supported to be clear about what their role is in making this happen and what support they need to achieve this.

**Top tips**

- Medical staff may make a multi-disciplinary decision for the individual to be supported by the Liverpool Care Pathway at this stage. This can then act as a trigger to review whether the individual's end of life care needs and wishes can best be met in their current setting
- Where possible, plan to have someone (a member of staff or a volunteer) available to sit with the dying person. This will provide them and their loved ones with comfort and reassurance
- Consider ways to support any family, friends or fellow service users that the individual wants to be present. For example, by providing, where possible, transport, accommodation, meals and emotional support. Liaise where necessary with those who support friends or family members who have a learning disability to ensure they are able to be as present as they and the dying person wishes them to be
- Support people with the same respect you would want for yourself or for a member of your own family.

*"I was able to go to my uncle's funeral, and say my goodbyes; I am not so angry now, and don't feel as sad I did. I am able to talk to my dad and his partner about my uncle Roy and this helps a lot. I also go to a 'life changes' course, run by a charity called BATIAS, which helps me deal with my bereavement. We make picture albums of our memories of people who we have lost and talk about how we can help other people as well."* Michelle Jones, health access champion for the Rayleigh and Castle Point area

Good end of life care does not stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to the wishes of family and friends. The support provided to relatives will help them cope with their loss and is essential to achieving a 'good death'. This support is also important for staff and other service users.

When the person who has died is a person with a learning disability there may be specific issues for family members due to the impact of the disability which may have affected individual emotional attachments and the whole structure of the family's life. This is likely to be particularly so if the learning disability is severe or has been accompanied with physical disability; in many cases the family will have lived with the prospect of the person's death for many years.

Where those who are left behind include people with a learning disability, then particular care needs to be taken to ensure they are supported to be as fully involved as they would wish to be; particular care needs to be given to the bereaved person's previous experience of death and the sense they have made of this.

## Issues to consider

- Have discussions concerning the death already taken place with other service users? Is there an awareness of those most likely to be vulnerable to complex grief due to previous experience or levels of understanding? Is there a plan in place to support them?
- Is there a clear plan to communicate the death to family members and other persons of significance bearing in mind that some of these may also have a learning disability and additional needs associated with this?
- Have sources of bereavement support (including those specifically for people with learning disabilities) been identified and is there accessible information about this support? Is there an established understanding within the organisation of what constitutes 'normal grief' and what issues or behaviours might suggest that the bereaved person might need additional bereavement support (either internally or externally; eg, Cruse) or to be referred on to a more specialist agency eg learning disability psychology/psychiatry departments?



Photo: Mencap 2011

## Your role

- Respect individuals' faith, beliefs and preferences, taking steps to meet their requirements
- Be aware of verification and certification of death policies
- Provide appropriate information to relatives, friends and carers about what to do after a death and provide practical support and guidance for those who require it (eg, in registering the death or contacting the funeral director to arrange the funeral or to view the body)[55]
- If friends or family members have never seen a dead body before it will be important to help them to understand what they are likely to see and the reasons why, prior to viewing the body. For people with learning disabilities seek out resources which explain additional considerations that should be taken into account[56]
- Offer information about bereavement support services and where necessary help to make the initial contact with these services
- Within a comfortable environment, facilitate the safe expression of other service users' questions, thoughts and feelings about the death
- Advocate, where appropriate, for those close to the deceased to be able to attend the funeral (if they want to) and offer alternative opportunities for remembrance and showing their respect
- Help family members to understand that the relationships between service users may have been very strong and might actually have been developed over significant periods of time in various service settings
- Whilst it is a normal inclination for family members to 'protect' their learning disabled loved ones from the knowledge and impact of bereavement this is likely to result in exclusion and to have an adverse effect on their grief. Therefore, staff should be prepared to share knowledge about healthy grief and the evidence that it is facilitated through supported involvement in the rites of passage (eg, funeral attendance) and, where necessary, to advocate in the best interest of the service user.

**Top tips**

- In some families the learning disability may have impacted on the emotional attachment of family members. Consequently there may be issues of guilt, anger and regret which may potentially complicate the grief of those non-learning-disabled family members left behind. It is vital not to express judgemental thoughts or behaviours which may be based on incomplete understandings of the family and which could exacerbate the distress of family grievers

- The bereavement history of many people with learning disabilities may not have been recorded by any of the services which they have accessed throughout their lives, and consequently there may be much which is unknown about how previous losses have been resolved. Previous losses may be reawakened by the current death and potentially complicate what might otherwise be an `ordinary' bereavement

- Remember that many adults with learning disabilities may never have attended a funeral before and therefore may be daunted by the prospect and may need support to do this[57]

- For some adults with a learning disability their understanding of death may be incomplete and they may consequently need additional help to understand the implications (eg, that death is a permanent state)

- Opportunities to acknowledge the death and to pay respect to the deceased are likely to be as important for learning disabled friends and family members as for those who do not have a learning disability. However, these may need to be adapted to the level of understanding of those taking part

- Clergy and funeral directors may not be aware of the need to use literal, non-euphemistic language to aid understanding in dealing with a bereaved person who has a learning disability; eg, the need to say 'died' rather than 'passed away'. There is a need to take the lead from the client with regard to the use of religious language. Eg, `heaven' for some service users will have a comforting meaning, for some it may cause confusion and for others it will hold no relevance at all

- People with learning disabilities are more likely to need a concrete focus for their remembering and therefore photographs and objects related to the deceased person are of great importance. This is especially so in settings where the person's dwelling may need to be reallocated in the short term

- It will not always be possible to tell in the short term who the death has had the most significance for. Some people with learning disabilities may appear relatively unaffected immediately after the death but six months or one year later may begin to express distress or depression related to the loss

- Deep distress as a result of bereavement may be expressed as challenging or self-injurious behaviour as well as in withdrawal, sleep deprivation or loss of appetite

- Wherever possible, the number of losses initiated by the death should be minimized so as not to complicate the grief of the learning disabled griever. For instance, multiple moves or a break from normal day-service settings[58]

- It will not always be necessary to have the services of a qualified bereavement counsellor. For many people the support of trained bereavement volunteers will be sufficient for them to be able to express and resolve their grief healthily.

**Case study**

A local authority day care service for elderly people with learning disabilities experienced a number of deaths within the course of a year. Although the service users had been together in this setting for only a few years, most of them had spent the majority of their lives together, firstly in long stay hospitals and latterly in the community, and so the loss of their peers was felt keenly.

As a result of the expressed wishes of family members of the deceased or constraints imposed by their various service settings not all had been able to attend all the funerals of their friends.

Over the months that passed the day service staff noticed how the bereavement had affected the various remaining members of the group. In response they set up a bereavement group where together people could share memories of the deceased and talk about how their deaths had made them feel. To give them a concrete focus for their remembering the staff developed a memory wall with photographs and mementos of the people who had died. This enabled the remaining friends to go somewhere when they wanted to remember or think about those who had died and, if requested, to have the support of the staff about how this made them feel.

It provided an additional comfort for some who understood that this meant that when they died they would be remembered too.

*"Because I was helped by the Macmillan nurse to be able to stay with my dad whilst he was dying, when my mum became ill some years later I knew that I would be alright and that I could help to look after her"* Self advocate

- Identify how well your organisation is prepared for managing the needs of a person with learning disabilities who is reaching the end of their life

- What policies and referral pathways are in place now and how can they be improved?

- Share this information with all staff and family members who may be involved in the delivery of end of life care

- Consider if it would be useful for a dedicated person in the learning disability team to do a course in end of life care or bereavement counselling, and consider whether someone in the palliative care team should do a course in the needs of people with learning disabilities

- Look after yourself and each other. Build in time to talk about difficult situations

- Find out if there is any available training in your area

- Look at the available resources which are on the National End of Life Care Programme website http://www.endoflifecareforadults. nhs.uk/

- Check end of life care support sheets relevant to this publication.

## In summary

There are a number of challenges in providing best end of life care for people with learning disabilities which have helpfully been described as the "5 Cs"[59] these are listed below. Seeking to proactively address these challenges increases the chances of achieving what can be considered as a `good death' not just for the service user but for those that love them.

**Complexity:** Having a learning disability may complicate the care that is required and the knowledge which professionals require to be able to deliver it across a range of settings. Education and training is key for all those involved.

**Communication:** Learning disability and palliative care professionals each have their areas of expertise in terms of communication. Whilst these overlap there will be areas in which either team knows less than they need to in providing best end of life care for people with learning disabilities. Teamwork (which includes the person as a central member) will be crucial to ensure distress is minimised and best care, in keeping with the person's preferences, is achieved.

**Compliance:** Assumptions about the person's ability or desire to comply with treatments or in decision making can lead to the person not being offered the full range of interventions that they would if they did not have a learning disability. This might include some end of life care placements; eg, hospice day care. It will be important to consider that the 'non-compliant' behaviour may better be interpreted as an expression of how the individual is feeling and may indicate an unmet emotional or symptom-control need.

**Consent:** The person's capacity to understand and consent to various elements of end of life care may be impaired by their learning disability but is likely to be more seriously impaired by assumptions or over-protective attitudes of carers (both family and paid). Professionals will need to employ clear

Photo: Mencap 2011

thinking about what decisions need to be made by whom as well as a willingness to be creative in finding ways to help the person understand their options and be active in deciding which ones they prefer. Above all consideration needs to be given not just to the individual's level of cognitive ability but to their life experience and their previously expressed views and wishes on issues related to end of life care. This applies whether the person can make the decision themselves or whether carers need to act in their best interests.

**Choice:** Often deprived of choice about all aspects of their lives it is crucially important for everyone involved in the end of life care of someone with a learning disability to give primacy to the individual's choice. Whilst a professional's duty of care mitigates what is important **for** the person this should not be at the expense of a commitment to ensuring that what is important **to** them is also realised.

## Quality markers for end of life care

(*End of life care strategy: quality markers and measures for end of life care,* Department of Health, Jun 2009)

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.

2. Institute effective mechanisms to identify those who are approaching the end of life.

3. Ensure that people approaching the end of life are offered a care plan.

4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.

5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.

6. Have mechanisms in place to ensure that care for individuals is coordinated across organisational boundaries 24/7.

7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.

8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.

9. Adopt a standardised approach (Liverpool Care Pathway or equivalent) to care for people in the last days of life.

10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

## Support sheet Mental Capacity Act

Compiled from the *Mental Capacity Act 2005 code of practice* by Julie Foster, end of life care lead, Cumbria and Lancashire End of Life Care Network

The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

**The five statutory principles are:**
1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

**How should people be helped to make their own decisions?**
To help someone make a decision for themselves, check the following points:

**Providing relevant information**
Does the person have all the relevant information they need to make a particular decision? If they have a choice, have they been given information on all the alternatives?

**Communicating in an appropriate way**
Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)? Have different methods of communication been explored if required, including non-verbal communication? Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

**Assessing capacity**
Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity. Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

**Assessing ability to make a decision**
Does the person have a general understanding of what decision they need to make and why they need to make it? Does the person have a general understanding of the likely consequences of making, or not making, this decision? Is the person able to understand, retain, use and weigh up the information relevant to this decision? Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

**Assessing capacity to make more complex or serious decisions**
Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

*Common core competences and principles for health and social care workers working with adults at the end of life*, NEoLCP/Skills for Health/Skills for Care/Department of Health, 2009

*Advance decisions to refuse treatment: a guide for health and social care professionals*, NEoLCP/National Council for Palliative Care, 2008

*Planning for your future care: a guide*, NEoLCP/National Council for Palliative Care/University of Nottingham, 2009

*Our health our care our say: a new direction for community services*, Department of Health, 2006

*Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability*, Mencap, 2008

*End of life care strategy: quality markers and measures for end of life care*, Department of Health, 2009

*Transforming community services: ambition, action, achievement transforming end of life care*, Department of Health, 2009

Out-of-hours toolkit, Macmillan Learn Zone (online learning resources for professionals)

*Improving the patient experience: celebrating achievement: Enhancing the Healing Environment programme 2003-2005*, Department of Health/The King's Fund, 2006

*Information for commissioning end of life care*, National End of Life Care Programme, 2008

Foundations in palliative care resources, Macmillan Cancer Support

*A framework of National Occupational Standards to support common core competences and principles for health and social care workers working with adults at the end of life*, National End of Life Care Programme et al, 2010

*Improving supportive and palliative care for adults with cancer*, National Institute for Clinical Excellence, 2004

*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, Department of Health, 2008

*Putting people first: a shared vision and commitment to the transformation of adult social care*, Department of Health et al, 2007

My end of life book guidelines from the NHS Foundation Trust for Gloucestershire (tool for supporting individuals approaching end of life)

Dying (easyread information about death for people with learning disabilities), Easyhealth website

*People with learning disabilities in England 2010*, E Emerson et al, Improving Health and Lives: Learning Disability Observatory, 2010

*Treatment and care towards the end of life: good practice in decision making*, General Medical Council, 2010

# Websites for further information sources

CHANGE
www.changepeople.co.uk

Easyhealth
www.easyhealth.org.uk

Gold Standards Framework
http://www.goldstandardsframework.nhs.uk/

Help the hospices
www.helpthehospices.org.uk

The King's Fund
www.kingsfund.org.uk

The Liverpool Care Pathway for the Dying Patient (LCP)
www.liv.ac.uk/mcpcil/liverpool-care-pathway

Marie Curie Cancer Care
www.mariecurie.org.uk

Mencap
www.mencap.org.uk

The National Council for Palliative Care
www.ncpc.org.uk

National End of Life Care Programme
www.endoflifecareforadults.nhs.uk

*Cancer what's going to happen to me?*, A Chalmers/E Nowicki, due for publication by the Learning Disabilities Federation, spring 2011

*Caring for people with learning disabilities who are dying*, N Blackman/S Todd, 2005

*Loss and learning disability*, N Blackman, 2003

*People planning ahead: a guide to communicating healthcare and end of life wishes,* L Kingsbury, 2009

*Bereavement counselling for people with learning disabilities*, S Read, 2007

*Palliative care for people with learning disabilities,* S Read (editor), 2005

*Living with learning disabilities, dying with cancer: thirteen personal stories*, I Tuffrey-Wijne, 2009

*The hospital communication book,* Clear Communication People Ltd
Developed on behalf of the learning disability partnership board in Surrey, this document aims to help people who have difficulties understanding or communicating to get equal service in hospital. It includes Makaton symbols so that mainstream staff can both understand and use these in their interactions with people with learning disabilities. This document can be downloaded from the Clear Communication People website at www.communicationpeople.co.uk

**Advance care plan (ACP):** This is the document which arises as a result of the advance care planning process which is described as "a process of discussion between an individual and their care provider irrespective of discipline. The difference between ACP and more general planning is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration of the individual's condition." (*Advance care planning* (Support sheet 3), NEoLCP, 2010) This document should be regularly reviewed and communicated to key persons involved in the individual's end of life care.

**Advanced decision to refuse treatment (ADRT):** Individuals cannot demand that they receive specific treatments but have the right to refuse them. An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific medical treatment in whatever circumstances you specify. This can include the choice to refuse treatment even if doing so might put your life at risk. The advance decision to refuse treatment will not be used if you are able to make your own choices at the time that the treatment is needed and offered. The *Mental Capacity Act (2005)* lays out the ways in which these decisions must be communicated.

**Circle of support:** A circle of support is a group of people who meet together on a regular basis to help somebody accomplish certain personal visions or goals. The individual asks a number of people to work with him or her to overcome obstacles and to help open doors to new experiences and opportunities. The circle acts as a support around the person who, for one reason or another, is unable to achieve what they want out of life on their own.

The individual is in charge, deciding whom to invite to be in the circle, and when and how often to meet; a facilitator is often used to help with this. Facilitators are people who help to support the circle to meet and keep it running. A facilitator is essential to an effective circle meeting. The facilitator agrees to conduct the meeting by beginning the activities, keeping a record of the meeting and helping people make commitments to action.

Circle members can be family, friends, neighbours, other community members and service providers - basically anybody that the focus person wants to invite. The majority of people in a circle of support are not paid to be there. Circle members should be involved because they love and/or care enough about the focus person to give their time and energy to supporting and helping the individual to overcome obstacles and increase opportunities open to them. See http://www.circlesarounddundee.org.uk/pcp/circle.html.

**Do not attempt resuscitation (DNAR):** A do not resuscitate document, often called a living will, is a binding legal document that states that resuscitation should not be carried out in any of the following circumstances:
- Where it would be considered medically 'futile'. Eg, where someone has experienced a cardiac arrest and is likely to have another one irrespective of treatment. In this situation the person need not have a document but medical staff may have made that decision in advance and documented this within the patient's notes
- Where the person has an advance directive which states that they do not wish to be resuscitated in the particular situation which they are currently experiencing. Eg, they have advanced cancer or advanced dementia and a life-threatening infection

- Where someone entitled to make decisions on behalf of the patient by holding a health focused power of attorney for them decides that the patient would not wish to be resuscitated in the current situation.

**Gold Standards Framework (GSF):** The Gold Standards Framework is a systematic evidence-based approach to optimising the care for patients nearing the end of life delivered by general health and social care staff. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.

GSF improves the quality, co-ordination and organisation of care in primary care, care homes and acute hospitals. This enables more patients to receive the type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation. See http://www.goldstandardsframework.nhs.uk/.

**Independent mental capacity advocate (IMCA):** The Mental Capacity Act (2005) places a responsibility on local authorities to ensure that people who are assessed as lacking mental capacity have access to an independent advocate when they are having decisions made about them relating to:
- Serious medical treatment (SMT)
- Changes of NHS accommodation for 28 days or more
- Change of local authority accommodation for more than 8 weeks.

People can also access IMCA support in accommodation reviews and safeguarding adults situations or when they have no family or friends to represent them.

IMCAs meet with the person and try to assist them in communicating and being as involved as possible in the decision making process. IMCAs represent the wishes and feelings of the person and will consult with other people.

IMCAs check that those working with the person adhere to the main principles of the Mental Capacity Act and act as a safeguard for the person's rights.

IMCAs provide the decision maker with a written pre-decision report, making recommendations, and will visit the person again after the decision has been made and provide a written post-decision report. IMCAs will challenge decisions if necessary.

**The Liverpool Care Pathway (LCP):** The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life. It is a means to transfer the best quality for care of the dying from the hospice movement into other clinical areas, so that wherever the person is dying there can be an equitable model of care. The LCP has been implemented into hospitals, care homes, individuals' own homes/communities, and hospices. It is recommended as a best practice model, most recently by the Department of Health in the UK.

**Personal communication passport:** Personal communication passports were developed in 1991 as a new way of documenting and presenting information about children and adults with disabilities who were unable to speak for themselves. They have since come to be widely used in home, care, social work, health and education settings. Personal communication passports are a way of making sense of formal assessment information and recording the important things about a child or adult in an accessible and *person centred* way, and of supporting an individual's transitions between services. Importantly, also, a passport is more than the end product booklet. Creating a passport is a process. The decision to create and use a passport gives a clear focus for ongoing home/school liaison, partnership working with families, and interdisciplinary collaboration.

Passports aim to:
- Present the person positively as an individual, not as a set of problems or disabilities
- Provide a place for the person's own views and preferences to be recorded and drawn to the attention of others
- Reflect the person's unique character, sense of humour etc
- Describe the person's most effective means of communication and how others can best communicate with and support the person
- Draw together information from past and present and from different contexts to help staff and conversation partners understand the person and have successful interactions
- Place equal value on the views of all who know the person well, as well as the views of the specialist professionals.

**Person centred planning:** Person centred planning is a process of life planning for individuals based on the principles of inclusion and the social model of disability. In person centred planning the process, as well as the product, is owned and controlled by the person (and sometimes their closest family and friends). As there are no prescribed forms, tick boxes or checklists, the resulting plan of support is totally individual. It creates a comprehensive portrait of who the person is and what they want to do with their life and brings together all of the people who are important to the person, including family, friends, neighbours, support workers and other professionals involved in their lives.

**Preferred priorities for care (PPC):** This patient held document was designed to facilitate patient choice in relation to end of life issues. Through good communication and by documenting their choices, both patient and carers become empowered through the sharing of this information with all professionals involved in their care. The PPC document provides the opportunity to discuss difficult issues that may not otherwise

be addressed (to the detriment of patient care). The explicit recording of patients/carers wishes can form the basis of care planning in multi-disciplinary teams and other services, minimising inappropriate admissions and interventions.

The PPC also records services available, services being accessed and reasons for changes in the care trajectory. PPC is a process which facilitates service review, further empowering professionals to negotiate service requirements on the behalf of patients and becoming an integral part of service commissioning and design.

[1]  *Cancer and intellectual disability: a review of some key contextual issues*, J Hogg/I Tuffrey-Wijne, Journal of Applied Research in Intellectual Disabilities, Nov 2008

[2]  *Equal treatment: closing the gap: a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems* (Part 1 of the DRC's formal investigation report), Disability Rights Commission, 2006

[3]  *Social Trends No 35*, C Summerfield/B Gill, Office for National Statistics, 2005

[4]  *Valuing people: a new strategy for learning disability for the 21st century*, Department of Health, 2001

[5]  *Adults with learning difficulties in England 2003/4*, Emerson et al, NHS Health and Social Care Information Centre/Office for National Statistics, 2005

[6]  *Death by indifference: following up the Treat me right! report*, Mencap, 2007

[7]  *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*, Sir J Michael, 2008

[8 & 9]  *Equal treatment: closing the gap: a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems* (Part 1 of the DRC's formal investigation report), Disability Rights Commission, 2006

[10]  *Social Trends No 35*, C Summerfield/B Gill, Office for National Statistics, 2005

[11]  *Adults with learning difficulties in England 2003/4*, Emerson et al, NHS Health and Social Care Information Centre/Office for National Statistics, 2005

[12]  *Epilepsy*, D Chadwick, Journal of Neurology, Neurosurgery and Psychiatry, Mar 1994

[13]  *Health in Wales Survey 1996*, Welsh Office, 1996

[14]  *Services for people with learning disabilities and challenging behaviour or mental health needs (revised edition)* (The Mansell report), Department of Health, 2007

[15]  *Vision care requirements among intellectually disabled adults: a residence-based pilot study*, McCulloch et al, Journal of Intellectual Disability Research, Apr 1996

[16]  *The incidence and importance of hearing loss in people with severe learning disability: the evolution of a service*, S Yeates, British Journal of Learning Disabilities, Jun 1995

[17] *Identification of hearing impairment in people with a learning disability: from questioning to testing*, Lavis et al, British Journal of Learning Disabilities, Sep 1997

[18] *Mortality in the mentally handicapped: a 50 year survey at the Stoke Park group of hospitals (1930-1980)*, G Carter/J Jancar, Journal of Intellectual Disability Research, Jun 1983

[19] *Mortality in people with learning disability: risks, causes and death certification findings in London*, Hollins et al, Developmental Medicine and Child Neurology, Jan 1998

[20] *Mortality in a hospitalized mentally handicapped population: a 10-year survey*, Puri et al, Journal of Intellectual Disability Research, Oct 1995

[21] *Cancer and people with learning disabilities: the evidence from published studies and experiences from cancer services*, Hogg et al, British Institute of Learning Disabilities, Dec 2003

[22] *Cancer and intellectual disability: a review of some key contextual issues*, J Hogg/I Tuffrey-Wijne, Journal of Applied Research in Intellectual Disabilities, Nov 2008

[23] *Are persons with Down syndrome protected against some forms of cancer?*, S Day/D Satgé, Health News (website), Jul 2009

[24] *Equal treatment: closing the gap: a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems* (Part 1 of the DRC's formal investigation report), Disability Rights Commission, 2006

[25] *Psychiatric disorders in mental retardation*, W Fraser/M Nolan, in *Mental health in mental retardation: recent advances and practices*, N Bouras (editor), 1994

[26] *The prevalence of psychiatric morbidity in mentally retarded adults*, J Lund, Acta Psychiatrica Scandinavica, Dec 1985

[27] *Recent trends in incidence, morbidity and survival in Downs's syndrome*, C McGrother/B Marshall, Journal of Intellectual Disability Research, Feb 1990

[28] *Age specific prevalence, thyroid dysfunction and depressive symptomatology in adults with Down's syndrome and dementia*, V Prasher, International Journal of Geriatric Psychiatry, Jan 1995

[29] *Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia*, McCarron et al, Journal of Intellectual Disability Research, Jul 2005

[30] PCPLD Network (formerly the National Network for Palliative Care of People with Learning Disabilities (NNPCPLD))

[31] *Advance care planning: a guide for health and social care staff*, National End of Life Care Programme/University of Nottingham, 2008

[32] *Factsheet – person centred planning*, C Sweeney/H Sanderson, British Institute of Learning Disabilities, 2002

[33] *Mental Capacity Act (2005) code of practice,* Department for Constitutional Affairs, 2007

[34] Disability Distress Assessment Tool (DisDAT)

[35] Personal communication passports

[36] *Understanding distress in people with severe communication difficulties: developing and accessing the Disability Distress Assessment Tool (DisDAT)*, Regnard et al, Journal of Intellectual Disability Research, Apr 2007

[37] *Breaking bad news of cancer to people with learning disabilities*, L McEnhill, British Journal of Learning Disabilities, Sep 2008

[38] *Communication difficulties and intellectual disability in end-of-life care*, I Tuffrey-Wijne/L McEnhill, International Journal of Palliative Nursing, Apr 2008

[39] *Best interests at the end of life: practical guidance for best interests decision making and care planning at end of life (relating to the Mental Capacity Act (2005) England and Wales)*, C Hutchinson/J Foster, East Lancashire PCT/Central Lancashire PCT, 2008

[40] Gold Standards Framework

[41] *Personalisation through person-centred planning*, Department of Health, 2010

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[43] Making a will (Directgov guidance on wills including links to Citizens Advice Bureau guide to making a will and Age Concern fact sheet)

[44] *Independent mental capacity advocates* (Support sheet 17)*, National End of Life Care Programme, 2010

[45] Preferred priorities for care (PPC), National End of Life Care Programme, 2007

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[48] Valuing people now (Department of Health guidance) and PCP (Person centred planning in Hampshire website including resource and information pages)

49 *Action to take if an adult with a learning disability is refusing immediate life saving/emergency treatment*, Salford Primary Care Trust, 2007

50 People with learning disabilities as carers (information page on Inspired Services Publishing website)

51 *The GSF prognostic indicator guidance*, K Thomas, End of Life Care, Feb 2010

52 *Prognostic indicator guidance (revised Vs 5)*, Gold Standards Framework/Royal College of General Practitioners, 2008

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54 The Liverpool Care Pathway for the Dying Patient

55 What to do after a death (Directgov guidance)

56 *Visiting/viewing the body of a deceased patient*, Nash et al, End of Life Care, Feb 2008

57 *How far are people with learning disabilities involved in funeral rites?*, Raji et al, British Journal of Learning Disabilities, Mar 2003

58 *Am I allowed to cry? A study of bereavement amongst people who have learning difficulties*, M Oswin, 1991

59 *What can we do? A guide to offering care and support to people with a learning disability at the end of life (End of life care: a resource pack for those caring for or supporting people with a learning disability at the end of life)*, L Gibson/D Matthews, National End of Life Care Programme/Northumberland Tyne and Wear NHS Trust, 2007

www.endoflifecareforadults.nhs.uk