



Public Health  
England

# **Making reasonable adjustments to end of life care for people with learning disabilities**

# About Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

The Learning Disabilities Public Health Observatory (LDPHO) is one of a small number of specialist public health observatories that cover England. It was set up in April 2010, following a recommendation in the Report of the Independent Inquiry into Access to Healthcare for Learning Disabilities (the Michael Report). It is a collaboration between three organisations: Public Health England, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. The LDPHO became part of Public Health England in 2013.

This report is part of a series of reports written by the LDPHO ([www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)) focusing on reasonable adjustments in specific service areas. The aim of these reports is to make it easier for people to find and use reasonable adjustments, and to share good practice regarding implementation of reasonable adjustments.

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**Note:** All web links checked April 2014

## Easy Read summary



People with learning disabilities are living longer.

That is good news!

But everyone will die at some time.

Some people die suddenly, maybe after an accident.

Some people die after a long illness.

Some people die when they are very old.

So a person may know for some time that they are getting near the end of their life.





A person who is getting near the end of their life probably has lots of different people caring for them to help with:

- feeling as well as possible
- stopping pain or making pain less
- stopping other problems like feeling sick
- coping with feelings about dying like being sad or angry

Some services are just for people who are dying.



They are called “palliative care”.

Palliative care services can also help the family and friends of a person who is dying.

They can help everyone to understand what is happening and to plan ahead.



It is important for people to make a plan for the end of their lives.

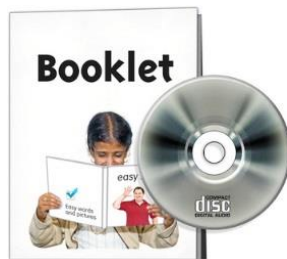
A plan might say things like:

- where you want to be when you die
- who you want with you
- how you want to be supported
- what you want to happen at your funeral



It is important that people are treated with dignity. This is about:

- being treated with care and respect
- having treatment explained in a way you understand
- getting the same treatment and care as everyone else



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities to use them.

This means services need to change so they are easier to use.



This report has lots of information about reasonable adjustments to help people have better care at the end of life.

Professionals and carers can use the information to make services better for people with learning disabilities.



This report has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities have better care at the end of life.

The pictures in this report are from Photosymbols: [www.photosymbols.co.uk](http://www.photosymbols.co.uk)



## Introduction

This report is about making reasonable adjustments in end of life care for people with learning disabilities.

Under English equalities law<sup>1,2</sup> public sector organisations are required to tailor the ways they provide care so that disabled people are not disadvantaged. Law governing the regulation of healthcare services is more explicit about the requirement for healthcare providers to ‘avoid unlawful discrimination including, where applicable, by providing for the making of reasonable adjustments in service provision to meet the service user’s individual needs’, and to have systems in place to enable them to assess and monitor the quality of the services provided regularly against this and other requirements.

Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with learning disabilities.

For example, people with learning disabilities may require clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed, help with appointments and help with managing issues of consent in line with the Mental Capacity Act. Public sector organisations should not simply wait and respond to difficulties as they emerge: the duty on them is ‘anticipatory’, meaning they have to think out what is likely to be needed in advance.

## People with learning disabilities and healthcare

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development<sup>3</sup>. It does not include conditions like dyslexia in which people have a specific difficulty with one type of skill but do not have wider intellectual impairment.



In England in 2012 approximately 1.1 million people had learning disabilities (236,000 children and young people, 908,000 adults)<sup>4</sup>. On average they have poorer health and die younger than other people<sup>5</sup>. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health-related behaviours and physical conditions often associated with causes of learning disabilities. It is also partly a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services. However, a significant factor is failure of health services to make reasonable adjustments, leading to lack of treatment or sub-optimal treatment<sup>6</sup> and poor experiences of healthcare<sup>7</sup>.

## End of life care for people with learning disabilities

### How we worked

We used the UK Health and Learning Disability Network<sup>8</sup>, a major e-mail network for people interested in better services for people with learning disabilities. We asked people to send us examples of reasonable adjustments they had made to services to improve end of life care for people with learning disabilities. We consulted the Palliative Care for People with Learning Disabilities Network<sup>9</sup>. We also looked at a number of websites (see the 'Resources' section of this report for more details), and did a short review of available research.

The next section of this report sets out the key messages from end of life care research; this is followed by a summary of relevant policy and guidance. Relevant national indicators are highlighted. We then list useful resources and provide examples of reasonable adjustments that have been made in different parts of the country to help improve end of life care services.

### Evidence and research

More people with learning disabilities are living into old age, and experiencing the range of health problems common in older people. More young people with complex health needs and life-limiting conditions are surviving into adulthood. There is increased

recognition of the high incidence of dementia in people with learning disabilities, especially people with Down's syndrome<sup>5</sup>. Along with these trends, there is growing awareness of the need for equal access to good end of life care for people with learning disabilities, but there is inequity of access to palliative care services for this group<sup>10</sup>.

Palliative care has been defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”<sup>11</sup>. In England end of life care is now the preferred Department of Health term<sup>12</sup>, possibly because the term palliative care has a historic connection to cancer, although the terms are often used interchangeably<sup>13</sup>.

People with learning disabilities experience many barriers to accessing quality health care for serious and terminal illness, including delayed diagnosis<sup>6</sup>. Evidence on access to effective end of life care by people with learning disabilities is sparse<sup>14-16</sup>. The recent Confidential Inquiry<sup>6</sup> showed that for almost a third of people with learning disabilities there were problems with their treatment or staff recognising that they were coming to the end of their lives. This meant that end of life care was not co-ordinated and the support for people and their families could have been improved. People with learning disabilities were less likely to have access to specialist palliative care services than a comparison group of people without learning disabilities; 20% of people with learning disabilities had received support from a specialist palliative care service and 10% had received support from a hospice (see also Stein, 2008<sup>17</sup>). Hospice, palliative care and end of life care professionals also report limited or no contact with people with learning disabilities and a lack of confidence in working with this group<sup>18-20</sup>.

Research has also found that professionals working with people with learning disabilities, such as nurses and social workers<sup>21,20,22</sup> report inadequate knowledge of good end of life care practice. Staff rarely discuss death and people's preferences for end of life care in advance<sup>22,23</sup>, for example in terms of breaking the news<sup>24</sup> and in communicating directly with the person with learning disabilities to make end of life decisions<sup>25</sup> rather than deferring to medical professionals or relatives<sup>26</sup>.

Staff also report difficulties in supporting people with learning disabilities and those around them through the end of life process<sup>27</sup> and continuing to support those around them after the person with learning disabilities has died<sup>28,29</sup>.

Negative consequences of this lack of access to effective end of life care support include a lack of timely diagnosis of life-limiting illnesses, a lack of timely advance planning that takes the preferences of the person with learning disabilities into account, poor pain management and access to opioids at the end of life, and end of life care taking place in unprepared acute hospital settings, resulting in considerable trauma for the person and family members<sup>14,6,30,31,16</sup>.

The key considerations<sup>32</sup> are thus:

- timely diagnosis and equal access to the full range of investigations and interventions
- skills to break bad news to the person with learning disabilities and support discussion of end of life care, in collaboration with their family carers and/or support services
- the needs of others (for example, where the person shares a house), including the needs of peers to understand what is happening and the needs of staff for support to continue to provide appropriate care
- support for palliative care services to understand the person's communication and other needs related to their learning disability
- good co-ordination, taking account of the complex range of issues there may be for a person with learning disabilities

## Policy and guidance

This section describes some of the policies and guidance available to support people with end of life care. People with learning disabilities should be able to access end of life care services, with appropriate reasonable adjustments, in ways that work equally as well as for people without learning disabilities.

### End of Life Care Strategy

In 2008 the Department of Health published the End of Life Care Strategy: promoting high quality care for all adults at the end of life<sup>33</sup>. This provided a framework on which health and social care services could build to improve end of life care.

Recommendations included a care pathway approach both for commissioning services and for delivery of integrated care for individuals. The suggested pathway involved the following steps:

- identification of people approaching the end of life and initiating discussions about preferences for end of life care
- care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly
- co-ordination of care
- delivery of high quality services in all locations
- management of the last days of life
- care after death, and
- support for carers, both during a person's illness and after death

Health and social care commissioners should conduct equality impact assessments of any planned changes to services.

### National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

The National Framework for NHS Continuing Healthcare (NHS CHC)<sup>34</sup> explains that people approaching the end of their lives may well meet the criteria for a 'primary health need' and eligibility for NHS CHC should always be considered. An individual who has a

rapidly deteriorating condition that may be entering the terminal phase may need NHS CHC funding to enable their needs to be met urgently (eg to allow them to go home to die, or for appropriate end of life support to be put in place). In these circumstances consideration should be given to use of the Fast Track Pathway Tool.

Recommendations for an urgent package of care via the fast-track process should be accepted and actioned immediately by the Clinical Commissioning Group (CCG). NHS CHC assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner, as part of the individual's overall end of life care pathway, with full attention to the individual's preferences (including those set out in advance care plans). Commissioners should take particular account of the Framework's guidance regarding person-centred commissioning and procurement arrangements.

## The National End of Life Care Programme

The National End of Life Care Programme<sup>35</sup> worked with health and social care staff, providers, commissioners and third sector organisations across England to improve end of life care for adults, helping to put into practice the End of Life Care Strategy and the NICE quality standard for end of life care for adults (see below). The programme produced a range of resources, such as the series 'The route to success: simple guides to support the implementation of the End of Life Care Pathway'. The series includes 'The route to success in end of life care – achieving quality for people with learning disabilities'<sup>36</sup>.

## One Chance to Get it Right

Following an independent review of the Liverpool Care Pathway for the Dying Patient, it was recommended that this should be phased out by July 2014. Subsequently, NHS England, as part of the Leadership Alliance for the Care of Dying People has developed a new approach to caring for people in the last few days and hours of life<sup>37</sup>. This document sets out the approach that should be used by health and social care organisations when providing care to dying people, irrespective of the setting in which someone is dying. The guidance focuses on the needs and wishes of those dying and the people closest to them, and is based on five new Priorities for Care for when it is thought that an individual may die within the next few days or hours. These five Priorities for Care put people and their families at the centre of decisions about their care and treatment.

## National indicators

The NHS Outcomes Framework 2013/14<sup>38</sup> includes a specific indicator (4.6) on improving the experience of care for people at the end of their lives.

This is supported by the objective stated in the NHS Mandate 2014-15<sup>39</sup>: “NHS England’s objective is to pursue the long-term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people’s lives.”

## NICE Quality Standard for End of Life Care

One of the four key recommendations in the End of Life Care Strategy was the development of quality standards against which providers could self-assess and be assessed by regulators. The National Institute for Clinical Excellence (NICE) subsequently developed the quality standard for end of life care (QS13)<sup>40</sup>. The quality standard is made up of 16 statements that describe high quality care. These are summarised below:

- people approaching the end of their life are identified at the right time so they receive care and support to meet their needs and preferences
- people approaching the end of life and their families and carers are communicated with, and offered information in a sensitive way, at a time when it is helpful and with respect for their needs and preferences
- people approaching the end of life are offered full assessments to ensure they are getting the best care and support for their circumstances
- people approaching the end of life receive treatment and care to manage their physical and psychological needs, at any time of day or night
- people approaching the end of life are offered social, practical and emotional support tailored to their needs and at the right time to help them feel supported, retain their independence and do things they enjoy for as long as possible
- people approaching the end of life are offered spiritual and/or religious support appropriate to their needs and preferences
- families and carers of people approaching the end of life have their own needs fully assessed as appropriate for their changing needs and preferences, and are offered support to help them cope

- people approaching the end of life receive care whenever they need it (day or night) that is consistent, smoothly co-ordinated and delivered by staff who are aware of their medical condition, care plan and preferences
- people approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care that takes into account their needs and preferences
- people approaching the end of life are offered specialist palliative care if their usual care team is unable to relieve their symptoms adequately; it is offered at the right time for them and is appropriate to their needs and preferences at any time of day or night
- people in the last days of life are identified and receive care according to their care plan, which takes into account their needs and preferences, and ensures they can have rapid access to all the support they need, including equipment (such as a pressure-relieving mattress) and medication
- the body of a person who has died is cared for in a culturally sensitive and dignified manner
- carers and family members of people who have died receive verification and certification of the death as soon as possible
- people closely affected by a death are communicated with in a sensitive way and offered bereavement, emotional and spiritual support appropriate to their needs and preferences; this may include information about practical arrangements and local support services, supportive conversations with staff, and in some cases referral for counselling or more specialist support
- people approaching the end of life and their families and carers are cared for and supported by staff with the knowledge, skills and attitudes needed to provide high-quality care
- People approaching the end of life and their families and carers receive high-quality care and support because there are enough staff with the right skills to meet their needs

This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of their life, regardless of disability.

## Quality markers for end of life care

A full set of quality markers was developed to support the End of Life Care Strategy<sup>41</sup>. These are summarised in Appendix 1 of 'The route to success in end of life care – achieving quality for people with learning disabilities'<sup>36</sup>.

## The 'Narrative for person centred coordinated care'

National Voices and Think Local Act Personal have collaborated on the 'Narrative for person centred coordinated care'<sup>42</sup>. Subsequently National Voices and the National Council for Palliative Care, working with a core group of voluntary organisations, have drafted (as at April 2014) a supplementary set of 'I' statements that describe some critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, their carers and families. These will be submitted to NHS England once completed. The working title is: Everyone working together to help me make the most of the last stage of my life.



## Resources

The following section lists some examples from practice and links to other resources that can be found on:

- the Easyhealth site: [www.easyhealth.org.uk](http://www.easyhealth.org.uk)
- the picture of health site: [www.apictureofhealth.southwest.nhs.uk](http://www.apictureofhealth.southwest.nhs.uk)
- the British Institute for Learning Disabilities site: [www.bild.org.uk](http://www.bild.org.uk)
- the Bereavement and Learning Disabilities site:  
[www.bereavementanddisability.org.uk](http://www.bereavementanddisability.org.uk)
- the Palliative Care for People with Learning Disabilities Network site: [www.pcpld.org](http://www.pcpld.org)
- the Access to Acute Network site: <http://a2anetwork.co.uk/>
- the Foundation for People with Learning Disabilities site:  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)
- the LDPHO reasonable adjustments database  
[www.improvinghealthandlives.org.uk/projects/reasonableadjustments](http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments)

The resources are in two sections:-

1. guidance and information
2. information for people with learning disabilities, family carers and supporters

Please note that some resources may be available from more than one site, but we have only included one link per resource. We have only listed resources that are free to download, although some sites include resources you can buy.

Theme	Description	Provider	Link
<b>Guidance and information</b>			
Bereavement and Learning Disability	Guide for professionals offering bereavement support	Keele University	<a href="http://www.bereavementanddisability.org.uk/">www.bereavementanddisability.org.uk/</a>
Living and Dying with Dignity	Ensuring people with disabilities receive inclusive end of life care services	Mencap	<a href="http://www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care">www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care</a>
Symptom Management	Symptom management end of life care pathway and guidance	Haringey Learning Disabilities Partnership	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=312">www.improvinghealthandlives.org.uk/adjustments/?adjustment=312</a>
End of Life Care	Dementia and end of life	Alzheimer's society	<a href="http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428">www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428</a>
Breaking Bad News	A suite of resources for use by practitioners, families and carers	Breaking Bad News	<a href="http://www.breakingbadnews.org/">www.breakingbadnews.org/</a>
Six Steps Structure	A programme for care homes to deliver the best end of life care	NHS Cumbria and Lancashire End of Life Care Network	<a href="http://www.endoflifecumbriaandlancashire.org.uk/six_steps.php">www.endoflifecumbriaandlancashire.org.uk/six_steps.php</a>
North West End of Life Care Model	Story of a patient's health from diagnosis to life limiting illness	NHS Cumbria and Lancashire End of Life Care Network	<a href="http://www.endoflifecumbriaandlancashire.org.uk/info_health_socialcare_professionals/model.php">www.endoflifecumbriaandlancashire.org.uk/info_health_socialcare_professionals/model.php</a>
Decision making	Deciding Right guide to support compliance with BMA/ Resuscitation Council/RCN joint statement on cardio-pulmonary decisions, NHS guidance on advance care planning and Mental Capacity Act	NHS England Northern Clinical Networks and Senate (End of life care network)	<a href="http://www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright">www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright</a>
Distress assessment	DisDAT tool provides means to document individual's language of distress, monitor their distress and evaluate its cause	St. Oswald's Hospice and Tyne & Wear NHS Trust	<a href="http://www.stoswaldsuk.org/adults/professionals/disdatt/Background%20to%20DisDAT/">www.stoswaldsuk.org/adults/professionals/disdatt/Background%20to%20DisDAT/</a>
Spiritual needs	Briefings on research about the spiritual needs of people	Foundation for People with	<a href="http://www.learningdisabilities.org.uk/publications">www.learningdisabilities.org.uk/publications</a>

	with learning disabilities	Learning Disabilities	<a href="#">/why-are-we-here-update/ www.learningdisabilities.org.uk/publications/what-about-faith-briefing/</a>
Palliative care services	Guidance for palliative care services on working with people with learning disabilities and co-working with learning disability services	Help the Hospices	<a href="#">www.helpthehospices.org.uk/our-services/publications/publications-catalogue/?entryid219=138181&amp;q=0~learning+disabilities~</a>
<b>Information for people with learning disabilities and carers</b>			
NICE quality standard	Information for patients and carers on improving support and palliative care for adults with cancer	NICE	<a href="http://guidance.nice.org.uk/CSGSP/PublicInfo/pdf/English">http://guidance.nice.org.uk/CSGSP/PublicInfo/pdf/English</a>
NHS Constitution	The principles and values of the NHS in England	Department of Health	<a href="http://www.gov.uk/government/publications/the-nhs-constitution-for-england">www.gov.uk/government/publications/the-nhs-constitution-for-england</a>
Dying Matters	We're living well but dying matters – videos	Dying Matters	<a href="http://www.dyingmatters.org/page/were-living-well-dying-matters">www.dyingmatters.org/page/were-living-well-dying-matters</a>
Living and Dying with Dignity	Ensuring people with disabilities receive inclusive end of life care services – easy read guide to accompany the guide for staff	Mencap	<a href="http://www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care">www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care</a>
When I die	Easy read choices booklet	Easyhealth	<a href="http://www.easyhealth.org.uk/listing/dying-%28leaflets%29">www.easyhealth.org.uk/listing/dying-%28leaflets%29</a>
Preferred Priorities for Care	Easy read booklet for anyone who wishes to plan for their future end of life care	Easyhealth	<a href="http://www.easyhealth.org.uk/listing/dying-%28leaflets%29">www.easyhealth.org.uk/listing/dying-%28leaflets%29</a>
My End of Life Book	Easy read booklet for end of life care planning	A Picture of Health	<a href="http://www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/">www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/</a>
End of Life Plan	Easy read end of life plan-what I want to happen	A Picture of Health	<a href="http://www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/">www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/</a>
End of Life Plan	Guidance for supporting	A Picture of	<a href="http://www.apictureofhealth">www.apictureofhealth</a>

Guidance	people to complete the end of life plan above.	Health	<a href="http://southwest.nhs.uk/acute-hospitals/end-of-life/">.southwest.nhs.uk/acute-hospitals/end-of-life/</a>
Hospice Care	Easy read information about hospice care	A Picture of Health	<a href="http://www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/">www.apictureofhealth.southwest.nhs.uk/acute-hospitals/end-of-life/</a>
End of life care resource pack	What can we do pack to help anyone supporting a person with learning disabilities during the end of their life, and after they have died	NHS North East	<a href="http://a2anetwork.co.uk/resources/palliative-careend-of-life-care/">http://a2anetwork.co.uk/resources/palliative-careend-of-life-care/</a>
Bereavement and Learning Disabilities	A guide for carers offering support	Keele University	<a href="http://www.bereavementanddisability.org.uk/">www.bereavementanddisability.org.uk/</a>
Bereavement and Learning Disabilities	Bereavement support for people with learning disabilities	Keele University	<a href="http://www.bereavementanddisability.org.uk/">www.bereavementanddisability.org.uk/</a>
Organ and Tissue Donation	Easy read leaflet about organ and tissue donation	NHS	<a href="http://www.organdonation.nhs.uk/newsroom/factsheets/">www.organdonation.nhs.uk/newsroom/factsheets/</a>
When I Die	Easy read person centred plan template	LDPHO	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=148">www.improvinghealthandlives.org.uk/adjustments/?adjustment=148</a>
My Final Plan	Easy read end of life plan template	LDPHO	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=107">www.improvinghealthandlives.org.uk/adjustments/?adjustment=107</a>
No box to tick	Booklet on meeting the spiritual needs and religious beliefs of people with learning disabilities	Foundation for People with Learning Disabilities	<a href="http://www.learningdisabilities.org.uk/publications/no-box-to-tick/">www.learningdisabilities.org.uk/publications/no-box-to-tick/</a>
What is important to you?	Easier read booklet on spiritual needs; includes section on loss and death	Foundation for People with Learning Disabilities	<a href="http://www.learningdisabilities.org.uk/publications/what-is-important/">www.learningdisabilities.org.uk/publications/what-is-important/</a>
Palliative Care, End of Life Care and Bereavement	Book for carers of people with learning disabilities affected by cancer	CHANGE	<a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>
Palliative Care, End of Life Care and Bereavement	Easy read book for people affected by cancer	CHANGE	<a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>

## Examples of reasonable adjustments and case studies

This section of the report demonstrates that making a variety of reasonable adjustments can improve the end of life care experience for individuals. The key themes that have been identified from the case studies of improved end of life care for people with learning disabilities include:

- multi-disciplinary team working
- easily accessible information
- supporting people to plan their end of life arrangements
- working in partnership with individuals and their families

A number of these case studies demonstrate that making reasonable adjustments for individuals can lead to effective systemic improvements.

### **Haringey Learning Disability Partnership**

Enjoying activities and spending money at the end of life

R is a 70 year old man with learning disabilities, dementia and lung cancer.

R had a substantial amount of money and no next of kin, but was not being supported to enjoy his money during the last few months of his life. With input from an Independent Mental Capacity Advocate, a learning disabilities nurse made a memory book with R so that he could be supported to spend his time and money doing activities he enjoyed. The nurse also worked jointly with palliative care teams and the GP to support them to understand R's communication and other needs, including issues relating to capacity.

R's health has deteriorated and he now lives in a nursing home, but the support he received meant that he had the opportunity to spend his time and money doing what he wanted to do before he became too ill.

## **Dorothy House Hospice, Winsley, Wiltshire**

### Accessible information

The Dorothy House Hospice team recognised that their information was not easily understood by people with learning disabilities. A small team formed to develop more accessible information: three people with learning disabilities, a member of the communications team (as graphic designer), a palliative care practice development nurse and representatives from each hospice department.

The following easy read leaflets have been produced by the team:

- ✓ About Dorothy House
- ✓ The Day Patient Unit
- ✓ The In-Patient Unit
- ✓ Hospice at Home
- ✓ Advance Care Planning
- ✓ Lymphoedema
- ✓ Breathlessness
- ✓ Complaints
- ✓ Complementary therapies

The team is working on leaflets about pain and other symptoms, such as fatigue, nausea and vomiting.

The team meets at the hospice every 6-8 weeks for 1½ hours and discusses words and pictures to explain the leaflet, for agreement by the three self advocates. The graphic designer works on changes for the next meeting, when the process is repeated to ensure everyone is pleased with the result and the look of the finished leaflet.

The team ensures that people with learning disabilities are offered information they can understand to help them make informed end of life care choices.

Further information can be found at: [www.dorothyhouse.co.uk/easy-read](http://www.dorothyhouse.co.uk/easy-read)

## **Calderstones Partnership NHS Foundation Trust**

### Involvement in planning end of life care

A had stage four lung cancer and learning disabilities; he was detained under the Mental Health Act and lived in a supported flat that was part of a secure service for

people with learning disabilities.

A had capacity and was able to make some decisions around what he wanted his end of life to be like. He wanted to die in the flat and he made an 'advance decision to refuse treatment' that was very specific. He completed a 'preferred priorities for care', and a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) was also completed. A made plans about his funeral by following the 'When I Die' document.

Following the 6 Steps Structure and using the End of Life North West Model of Care (see Resources/Guidance section of this report), A was cared for in his usual place of residence by the local Macmillan nurse, the onsite Advanced Practitioner, a Practice Educator and two psychiatrists.

Treatment and care plans were methodical, yet easy to follow, with clear instructions about what to do if different situations arose. Training was arranged to educate staff who were unfamiliar with A (who might have to make decisions in emergencies), to prevent inappropriate admissions to hospital and to promote A's wishes to die at home and not alone.

Although A did get admitted to hospital, two staff stayed with him and his wish not to die alone was achieved with the support of his care staff.

## **Bradford District Care Trust**

Support for the whole family

M lived at home with his elderly mother, and shared a bedroom with his brother. Both M and his brother had moderate learning disabilities and their mother had looked after them all their lives. In his late fifties M developed a tumour in his stomach. M would not tolerate a CT scan even with sedation. Finally it was decided through a best interests process that M would not be able to understand or tolerate the post-operative aftercare that would be required if he had surgery and palliative care was felt to be the preferred option.

M began attending the Marie Curie day centre one day a week so that he could build relationships with the palliative care staff and get used to the hospice. At first he stood outside in the hospice garden, wary and watching what was going on but refusing to participate. Eventually he was encouraged to go inside and interact. Staff found M a job

assisting domestic staff; he enjoyed this and it helped him become familiar with the whole hospice.

As the tumour grew it affected M's appetite: he was eating less and losing weight, so he was admitted to the hospice. M was in great pain; the palliative care nurse administered morphine with the assistance of the learning disability nurse, as M needed to be restrained safely in order to have the pain relief administered.

M began eating and drinking small amounts again and returned home. A contingency plan/pathway was put in place, involving palliative care, district nursing and the learning disabilities team. Morphine injections were stored safely at M's home and the learning disabilities nurse obtained a list of volunteers trained in safe holding techniques to call upon in case assistance was needed.

M's illness progressed and he became unsteady on his feet. He fell down the stairs twice and was re-admitted to the hospice. Within a couple of days his health deteriorated further and in the early hours of one morning the hospice contacted both the learning disabilities nurse and M's mother; the nurse took both M's mother and his brother to the hospice.

It was felt that that watching M die would be too frightening for his brother, so the learning disabilities nurse sat with him in the conservatory while M's mother stayed with M and was with him when he died. The learning disabilities nurse then suggested that M's brother should be allowed to see him, so he could understand that M was no longer there and would not be coming home to the bedroom they had shared for 50 years. M's brother saw M's peaceful body and then he hugged their mother. He seemed to understand and it was a very moving experience for all concerned.

The learning disabilities nurse took mother and son home and supported them through registering the death and making the funeral arrangements. The nurse took M's mother to see M in the chapel of rest and attended his funeral. Thus both M and his family were supported through his illness and death.

## **Hft, Cheshire and Merseyside**

Support for mother and daughter

A was 44 years old and had lived at home with her mother all of her life. She had



multiple brain tumours, which had a profound effect on her personality and behaviour. Coupled with mum's own ill health, this meant that A needed to move into her own bungalow with her own team of staff. It was recognised as a huge issue for both of them and arrangements were made for mum to stay over as and when she felt able, giving them time together to talk about the end of life that they both acknowledged was coming. This included planning an end of life pathway for A, supported by the Macmillan nurse. Mum felt strongly that A should not go into hospital at the end; this was agreed and written up with support from the GP and consultant.

A had periods of stability when she enjoyed going to the supermarket for her shopping and loved buying DVDs and playing cards. When her illness made this difficult, a specialist occupational therapist suggested extra activities at home, including growing plants from seed and cooking. A really enjoyed seeing the end result of her baking, often inviting people who lived close by to come and share her cakes with a cup of tea. Seeing her herbs and other plants grow also seemed to give her a sense of achievement and calm.

Sudden deterioration in mum's health made it impossible for mum to visit; A found this hard to understand. Eventually mum agreed that a meeting to say goodbye should be facilitated. Following this A was able to express her grief and she was supported to make a memory box. Photographs of A doing the things she liked were put in an album for her mum, offering reassurance that A was coping and getting on with her life.

The health of A and her mum deteriorated within weeks of each other; A suddenly became immobile following a seizure and developed a high temperature. An ambulance was called on the advice of the GP; A was admitted to hospital and a brain scan revealed an escalation in the tumours. A's staff continued to support her at the hospital 24 hours a day; this proved reassuring for A and provided a consistency that was invaluable to A when she was feeling at her most vulnerable.

Soon A became unconscious and the team were unsure whether she was aware that her mum had been admitted to the same hospital and had died. Several days later A also passed away with a staff member by her bedside.

It would have been wonderful for A to have passed away in her own home, but the best laid plans are not always possible. A's team were with her right to the end of her life and were a source of comfort, consistency and reassurance to A when she was unwell and possibly afraid.

## **Hft, Cheshire and Merseyside**

### Support to die at home

B was a 46 year old man with Down's Syndrome who had been supported for over 20 years to have a full and active life. At the age of 43 B was diagnosed with early onset dementia; medication helped for a while, but its effectiveness diminished over time. This began to have an impact on the people B lived with, so the Community Learning Disabilities Team arranged for a specialist practitioner to talk to the other people living in the house about dementia and explain what was likely to happen to B.

B had a seizure and was admitted to hospital; he lost the use of one side of his body and was no longer mobile. This meant that he was unable to return to his own home, as he had an upstairs bedroom, so a two bedroom bungalow was found for him.

B remained in hospital for some weeks; during that time, the manager from Hft met with the funding authority and B's family to discuss him returning home. There was a suggestion he should go into a nursing home; however, a reasoned argument was presented and funding was agreed for B to move into the bungalow with a familiar team of people around him. B's family were able to come and stay with him, cook meals, sleep over and relax. This enabled B to have a family Christmas and his girlfriend was also able to come and sit with him and spend time saying goodbye.

B's team continued to work collaboratively with the Community Learning Disabilities Team, the Palliative Care team and the GP surgery to ensure that B was receiving the best possible care and support. Staff were offered bereavement training and support, as it was acknowledged that the work they were doing was extremely complex and challenging.

B passed away peacefully with his family around him and his favourite Elvis track playing in the background. The team felt passionately that, even though it was obvious that B was near the end of his life, he should be given the opportunity to come home to where he was comfortable, where people knew him and where his family could spend time with him in comfort.

## **Surrey and Borders Partnership NHS Foundation Trust**

### Living with dementia, dying at home

G had Down's syndrome and was diagnosed with Alzheimer's disease in February 2009. He lived in a small residential home with three other men. He had a comprehensive care plan, Health Action Plan and detailed Hospital Passport so that staff could ensure he was supported in the way that he wanted even at the end of his life. G was supported to have regular contact with his mum and sister, who had their own long term health issues.

Even though G had late stage dementia, he had an active social life and, when he was feeling well and alert, he was supported to participate in his preferred activities. The team had noticed, when using his life story book, that he was showing an interest in his pictures of football and they knew that he had always supported Chelsea Football Club. They arranged for him to attend a Champions League Match one evening at Stamford Bridge. By now G was completely reliant on a Rhea Assist Wheelchair, hoist and two members of staff to support him with personal care. G was 'double dressed' for the evening in two layers of clothing to keep him warm. G's face lit up when he was shown the Chelsea Football shirt that his care team had got him with his name on the back.

Staff were concerned that the journey and noise would be too much for him, but they had done a thorough risk assessment and contingency plans. G had a wonderful time and stayed awake from the moment he left home to the moment he returned. By the next morning, the photos of him at the event had been added to his life story book.

Throughout the course of G's dementia and his end of life care the Community Team for People with Learning Disabilities were closely involved in helping to guide his care. Quarterly reviews took place throughout the course of his dementia with the focus on forward planning so that the staff team were prepared for all eventualities.

G's dementia progressed and he experienced frequent chest infections. He went into hospital for a week, but staff were adamant that he was coming home to die, as written in his person centred plan. G was able to return home, where he was cared for until he died peacefully in his sleep ten days later, with his staff team and friends around him.

The team helped to prepare him for the funeral, which was conducted exactly as G had planned – with a humanist ceremony, a black coffin, music by Elvis Presley and a Dalek on the wreath on his coffin.

## **Kent Community Health Trust**

### Cancer treatment and support to minimise distress

C had severe learning disabilities, autism, blindness and cancer of the vulva, confirmed after a best interests meeting and surgery. A further best interests meeting concluded that a radical vulvectomy was required.

Community learning disability staff worked with staff from the acute hospital ward and agreed the following reasonable adjustments:

- first on list
- pre-med to be used
- gas induction for anaesthesia
- wear own clothes
- side ward
- sedation post operatively due to possible distress about the catheter

Post-operatively it was agreed that frequent showers would be required to manage the risk of infection, due to the nature of the surgery and C being doubly incontinent. The surgery went to plan and all reasonable adjustments were implemented; the experience was positive for C and minimal stress was caused.

Unfortunately the cancer returned and was aggressive in nature. C was unable to tolerate daily radiotherapy without a general anaesthetic and palliative care was agreed. This included further surgery to remove a mass in her groin; again, all reasonable adjustments were implemented effectively.

The disease progressed rapidly. A referral was made to Margate hospice and a meeting was arranged to discuss management, as staff caring for C were very anxious due to the nature of the cancer and difficulties in managing C's condition. Joint training was arranged for learning disability nursing and hospice staff to discuss anxieties and to explore how C could be enabled to have a good death. This training and continued collaboration helped to reduce staff team anxiety and thereby improved care for C, who was pain free and comfortable at the time of writing.

This case demonstrates how effective joint working and reasonable adjustments can enable a person to have positive and distress-free experiences within acute hospital settings and to plan for a good death.

## **Kent Community Health Trust**

Hospice care – learning from experience

F was referred to community learning disability nursing for support to explore her diagnosis and end of life care, as she had a rare and incurable heart condition. F was thought to be either in denial or unable to understand the concept of death.

Several weeks were spent developing rapport with F to explore experiences of death, in order to establish what she knew. Work followed on her diagnosis and what that meant for her. From this it was clear that, although F had a good basic understanding of death, she was unable to transfer this concept to herself. She was supported using Books Beyond Words to develop a story about a man who was dying. She was then supported to develop her own story, relating to her own diagnosis and dying. This was effective in helping her to transfer the concept to herself and with support she was then able to explore the document 'I am Dying' and to put on paper what she wanted to happen. All this was done using pictures and easy read information.

F was referred to a hospice and visited, supported by the Community Learning Disability Nurses. Unfortunately this visit did not go well and resulted in F becoming distressed and refusing to discuss anything involved with the hospice. She thought the hospice was a hospital and she did not wish to die in hospital. Also, issues around Do Not Attempt Resuscitation (DNAR) were discussed in too much detail. It was thought that lack of familiarity amongst hospice staff in working with people with learning disabilities contributed to this difficult experience for F.

Supported through joint working, the hospice is now trying to work with F to alleviate her fears. This process will take time and a low key approach is being adopted. Previous work with F is being revisited, as her thinking about dying had gone backwards.

F is being supported to develop a PowerPoint presentation about palliative care for people with learning disabilities. As a result of her experience, learning disabilities training is being offered to all hospice staff and improvements in joint working are being sought.

## **East Kent Hospitals University Foundation Trust**

Reasonable adjustments in use of communication tools

J was a 57 year old man with cerebral palsy and profound and multiple learning disabilities. J was admitted to hospital following a period of sickness and some loss of

weight.

J was flagged as having a learning disability on the Special Register on the hospital's Patient Administration System, so the Practice Development Nurse for people with learning disabilities (PDN) was alerted to his admission. The PDN visited J and reviewed his care up to that point against the 4Cs Framework for making reasonable adjustments (Communication, Choice making, Collaboration and Coordination - see [www.trustnewsline.org/we-care/2013/08/learning-disability-week-ekhuft-superheroes/](http://www.trustnewsline.org/we-care/2013/08/learning-disability-week-ekhuft-superheroes/)).

Staff sourced a Hospital Communication Book and 'My Healthcare Passport' – a tool developed by, and with, people with learning disabilities in East Kent to enable ward staff to understand those who might not be able to give a full verbal history. The Hospital Communication Book proved to be a vital tool for J: he was able to use it to get his message across, reducing reliance on care staff to interpret communications. The book facilitated a working and caring relationship between J and ward staff.

A few weeks later J was re-admitted; the PDN was again automatically alerted, visited the ward and met with the ward sister and learning disability ward champion. J's care staff had written out some of his likes and dislikes, which the ward team found useful. An endoscopy was proposed. The senior house officer, nursing staff, care workers and J met and the Communication Book was used to facilitate the conversation. J looked concerned, pointing to his teeth, and the care worker explained that J liked to take care of his teeth so he might be anxious about them. Information was left with J and his supporters overnight before the doctor returned to assess J's capacity to consent. Great care was taken over this. J had clearly understood and retained the information he had received the previous day; he was anxious about the camera going into his mouth and damaging his teeth. He expressed that he did not want the procedure.

The consultant decided to wait for 24 hours and then to review J's decision with the speech and language therapist who knew J. After reflection with his carers and supporters J eventually chose to have the procedure and it was done that day. A lump was found, so the consultant invited the care home team to be with J when the results were shared. The hospital had a store of easy to read information and this was used to share the information of his diagnosis with J and his carers. J had the possible procedures explained to him and, with support from the care home staff, he agreed to these. There were concerns about his ability to cope with the anaesthetic and J passed away on the day they were due to assess him, with his carers and the ward staff at his bedside.

Ward staff had built up rapport with J and his carers, which enabled them to provide the most holistic, patient centred care possible. Staff were able to identify J's fears, anxieties and needs by using the Hospital Communication Book. This shows what can be done to ensure that people with learning disabilities receive a service that is person centred. Simple adjustments – in his case, communication techniques – enabled J to experience a service working with him rather than on him.

## North East England

Network action across a region

A network approach across the North East has supported a range of effective action:

The End of Life Care Clinical Network developed the Deciding right initiative (see Resources) to improve decision making with and for individuals and their families as part of end of life care planning. Poor decision making, especially for care decisions made in advance, is often characterised by a lack of compliance with national guidance and legislation. Deciding right enables individuals and organisations to be compliant with the 2007 BMA/Resuscitation Council/RCN joint statement on cardiopulmonary decisions, the 2011 NHS guidance on advance care planning and the 2005 Mental Capacity Act. Since 2012 Deciding right has been adopted by all NHS and many healthcare organisations in the north east, Cumbria, north Lancashire and the Wirral in Cheshire. The key principles of Deciding right are:

- care decisions centred on the individual rather than the organisation
- strong partnership between the individual, carer or parent and the health or social care professional
- decisions made for people who lack capacity follow the requirements of the Mental Capacity Act
- consistent decision documentation (Do Not Attempt Cardiopulmonary Resuscitation and Advance Decision to Refuse Treatment) used in all care settings
- Emergency Health Care Plans used to tailor care to the individual
- choices about treatment are agreed and honoured
- principles and documentation developed to be suitable for all ages

Development of the What can we do? resource pack (see Resources) was also a regional initiative to provide information and support to family carers and staff

supporting someone with a learning disability.

Across the North East each locality has developed cross-sector pathways for people with Down's syndrome and dementia.

Northumberland Tyne and Wear NHS Foundation Trust hosts the only Macmillan nurse post for people with learning disability, focused on clinical practice, education/training and service development. The service acts as a resource to learning disability and generic services across Northumberland as well as providing specialist palliative care advice and support to people with learning disabilities who have a diagnosis of end stage disease.

This range of activity across the North East, supported by expertise from St Oswald's Hospice, demonstrates the value of an active improvement network.

### **Leicester, Leicestershire and Rutland**

Collaboration to improve support across primary and acute care

Learning disability liaison nurses in primary care and the acute sector have collaborated with colleagues across Leicester, Leicestershire and Rutland (LLR) over a number of years to promote good practice in end of life care and to improve the confidence of family carers and support providers. A two day conference was organised in 2012 with the LLR End of Life Trainer, including practical sessions for participants to work on issues themselves. The event also included a workshop for people with learning disabilities, facilitated by CHANGE, to talk about death and dying. An End of Life Handbook has been developed, led by the Practice Development Nurse, and is being promoted across services. At the time of writing the Learning Disability Primary Care Liaison Nurse and Learning Disability Acute Liaison Nurse are undertaking a survey on pain assessment tools and promoting use of the DisDAT (see Resources).

### **Berkshire**

End of life care training for care workers

Berkshire Healthcare NHS Foundation Trust formed an end of life care working group bringing together learning disability nurses, Macmillan staff and Sue Ryder Care. They



scoped availability of services and gaps in order to develop an action plan. One of the first priorities agreed was training for care workers from a range of services for people with learning disabilities, such as residential care, day services, short breaks and supported living. This priority was derived from research evidence about the needs of care workers, including: recognising and managing distress and pain; working with family carers and supporting other people with learning disabilities, and managing the emotional impact on themselves and others.

Study days were offered, delivered by staff from learning disability nursing, palliative care services and primary care. Each day covered:

- end of life care (and identifying end of life as a stage)
- people with learning disabilities talking about their wishes and advance care plans
- availability of local services
- the impact of care workers' own beliefs, values and needs in relation to death and dying
- physical, psychological, spiritual and social issues related to care for a dying person

The days stimulated discussion about consent and capacity (including capacity to plan ahead), recognising pain, and barriers and solutions in delivering end of life care. Staff were supported to acknowledge their fears and gain confidence in their own skills and in understanding the services and supports available.

## Conclusion

People with learning disabilities are less likely to benefit from palliative care services than their non-disabled peers. Therefore it is important to put reasonable adjustments to palliative care and end of life care services in place so that people with learning disabilities have improved end of life care experiences. Clinical Commissioning Groups should take account of this in their commissioning for end of life care.

This report signposts professionals, support workers and family carers to numerous resources that can be used to enable people with learning disabilities to experience quality care at the end of life. These resources provide examples of arrangements that have been developed at both individual and system wide levels.

## Acknowledgements

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