



# Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities



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## About Public Health England

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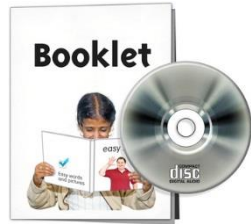
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# Easy Read Summary

	<p>What is dementia? Dementia is the name of an illness in the brain. People who have dementia forget how to do things. They also forget things they did in the past.</p>
	<p>People with learning disabilities are five times more likely to develop dementia than people without learning disabilities.</p>
	<p>It can be difficult for people with dementia and family carers to get the right support.</p>



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use them. This means they need to change their services so they are easier to use.



This report has lots of information about reasonable adjustments in dementia services. Professionals and carers can use them to get better services for people with learning disabilities and dementia.



The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities and dementia can use dementia services.

# Improving Health and Lives

## Reasonable Adjustments Briefing

Improving Health and Lives (IHAL) aims to get better data and information about the health and healthcare of people with learning disabilities, and supports commissioners, providers and others to use this information. 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).<sup>1</sup>

IHAL is a collaboration between three organisations: Public Health England, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Public Health England was established on 1 April 2013 bringing together more than 70 organisations into a single public health service. It works with national and local government, industry and the NHS to improve the nation's health and support healthier choices. Public Health England addresses inequalities by focusing on removing barriers to good health.

This report is the fifth in a series focusing on how health services can make specific areas of healthcare better and easier for people with learning disabilities to use. The aim is to share ideas and good practice in areas of healthcare that are particularly important and difficult. More details are available from our database of Reasonable Adjustments, which is available at [www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/)

## Reasonable Adjustments

Under English laws about equalities, public sector organisations have to tailor the way they provide care so that disabled people are not at a disadvantage. This may mean making physical adjustments to buildings such as providing lifts, wide doors and ramps. Importantly, it also means making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities. As far as possible, public sector organisations have to think about what might be needed in advance, not wait until people get into difficulties or ask for help. Training staff about what people with learning disabilities are likely to need is a good start.

## People with learning disabilities and healthcare

By learning disabilities, we mean a significant general impairment in intellectual functioning (typically defined as having an IQ of less than 70) starting in childhood.<sup>2</sup> It does not include conditions like dyslexia where people have a specific difficulty with one type of skill but do not have wider intellectual impairment.

In England, approximately 1.2 million people have learning disabilities (290,000 children, 900,000 adults).<sup>3</sup> On average, people with learning disabilities have poorer health and die younger than others.<sup>3-7</sup>

A lot of reports have shown that people with learning disabilities get worse healthcare than others.

# Dementia and People with Learning Disabilities

## Evidence and Research

Dementia in people with learning disabilities is becoming more common. This is because:

1. Dementia becomes more common as people get older and people with learning disabilities are living longer.
2. People with a learning disability are five times more likely to develop dementia as they get older compared to the general population.<sup>38</sup>
3. People with Down's syndrome have a specific additional risk of developing dementia. For them, this often happens at ages from 35 to 45 onwards.<sup>40</sup>

The growing number of people living with both a learning disability and dementia means that commissioners and providers need to plan to ensure the right support is available in sufficient quantities. Some people with learning disabilities begin to develop dementia while still living with family carers. They may also need support.



## Policy and Guidance

This section describes some of the policies and guidance available to support people with dementia. People with learning disabilities should be able to access dementia services, with appropriate reasonable adjustments in a way which works equally as well as for people without learning disabilities.

- National Institute for Clinical Excellence (NICE) guidance for the clinical management of dementia is available at: <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/English>
- A commissioning guide for people with dementia produced by the Royal College of General Practitioners is available at: [www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~media/Files/CIRC/LD%20Commissioning/RCGP%20LD%20Commissioning%20Guide%20v1%200%202012%2009%2024%20FINAL%20pdf.ashx](http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~media/Files/CIRC/LD%20Commissioning/RCGP%20LD%20Commissioning%20Guide%20v1%200%202012%2009%2024%20FINAL%20pdf.ashx)
- The Dementia and People with Learning Disabilities Charter details the requirements of the National Dementia Strategy and required outcomes. [www.friendsaction.co.uk/resources/dementia-and-people-learning-disabilities-charter](http://www.friendsaction.co.uk/resources/dementia-and-people-learning-disabilities-charter)

In the USA, the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices was formed as a response to the National Alzheimer's Project Act (NAPA). One objective of the NTG is to highlight the additional needs of individuals with intellectual and developmental disabilities who are affected or will be affected by Alzheimer's disease and related disorders. The work includes:

- The early detection of dementia;
- Recommendations for the evaluation and management of dementia for people with intellectual disabilities;
- A national strategy for people with intellectual disabilities and dementia to remain their communities and receive quality support, and Guidelines for community care and support.

A link to further information can be found in the Resources section of this report on page 11.

## National Indicators

The Public Health Outcomes Framework for 2013–16<sup>48</sup> includes the following indicator under Domain 4: Healthcare public health and reducing premature mortality: *‘Reduced number of people living with preventable ill health and people dying prematurely while reducing the gap between communities.’*

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/193619/Improving-outcomes-and-supporting-transparency-part-1A.pdf.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193619/Improving-outcomes-and-supporting-transparency-part-1A.pdf.pdf)

The Department of Health Mandate to the NHS Commissioning Board 2013-2015 includes indicators for both the premature deaths of people with learning disabilities and enhancing the quality of life for people with dementia.

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127193/mandate.pdf.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf)

The NHS Outcome Framework 2013/14 also includes the following indicators: 1.7 *Reducing the premature deaths of people with a learning disability* and 2.8 *Enhancing the quality of life for people with dementia*

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213055/121109-NHS-Outcomes-Framework-2013-14.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213055/121109-NHS-Outcomes-Framework-2013-14.pdf)

## Resources

The following sub-sections include some examples from practice, resources and links to other easy read resources, which 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 Alzheimer’s Society site [www.alzheimers.org.uk](http://www.alzheimers.org.uk); the Down’s Syndrome site: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk); the British Institute for Learning Disabilities site: [www.bild.org.uk](http://www.bild.org.uk); the Royal College of Psychiatrists site: [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk) and the LDPHO reasonable adjustments database [www.improvinghealthandlives.org.uk/projects/reasonableadjustments](http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments)

The resources are in four key sections:-

1. Strategy and outcome measures
2. Guidance and information
3. Supporting people
4. Information leaflets

Please note, some resources may be available from more than one site, but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

Theme	Description	Provider	Link
<b>Strategy &amp; Outcome Measures</b>			
Living Well with Dementia	Department of Health Dementia Strategy	Department of Health	<a href="http://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy">www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy</a>
Quality outcome measures for people with dementia	Measuring the quality of outcomes for people with dementia	Faculty for Learning Disabilities	<a href="http://dcp-ld.bps.org.uk">http://dcp-ld.bps.org.uk</a>

<b>Guidance and Information</b>			
Ageing and people with learning disabilities	Ageing and its consequences for people with Down's Syndrome	Down's Syndrome Association	<a href="http://www.downs-syndrome.org.uk">www.downs-syndrome.org.uk</a>
Information pack	Structured dementia information pack for people with learning disabilities and family carers	Dudley Community Services	<a href="http://www.improvinghealthandlives.org.uk">www.improvinghealthandlives.org.uk</a>
Dementia and people with learning disabilities	Guidance on the assessment and diagnosis, treatment and support of people with learning disabilities who develop dementia	Royal College of Psychiatrists	<a href="http://www.rcpsych.ac.uk">www.rcpsych.ac.uk</a>
Royal College of Nursing Dementia Information	Dementia information and supporting resources	Royal College of Nursing	<a href="http://www.rcn.org.uk">www.rcn.org.uk</a>
Dementia pathway	Learning disabilities assessment pathway flowchart	NHS Kent and Medway	<a href="http://www.improvinghealthandlives.org.uk">www.improvinghealthandlives.org.uk</a> Case study on page 15 of this report.
Down's Syndrome and dementia	Psychosocial interventions for people with Down's Syndrome and dementia	Foundation for People with Learning Disabilities	<a href="http://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a>
Health in later years	Health in later years for people with learning disabilities	Mencap	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Living with dementia	Video about dementia	NHS Choices	<a href="http://www.easyhealth.org.uk/content/living-dementia">www.easyhealth.org.uk/content/living-dementia</a>

Home for good	Preparing to support people with learning disabilities in residential settings when they develop dementia	Joseph Rowntree Foundation	<a href="http://www.jrf.org.uk">www.jrf.org.uk</a>
Care and detection screening	Guidelines for structuring community care and support and early detection screen for dementia	National Taskforce on Intellectual Disabilities and Dementia Practices	<a href="http://aadmd.org/ntg">http://aadmd.org/ntg</a>
<b>Supporting People</b>			
Supporting Derek	For staff working with people who have a learning disability and dementia	Joseph Rowntree Foundation	<a href="http://www.jrf.org.uk">www.jrf.org.uk</a>
Hot tips	Tips for supporting people with dementia	MacIntyre Charity	<a href="http://www.improvinghealthandlives.org.uk">www.improvinghealthandlives.org.uk</a> Case study on page 16 of this report.
<b>Information Leaflets</b>			
Carers	Information for carers	Cheshire and Wirral Partnership NHS Foundation Trust	<a href="http://www.easyhealth.org.uk">www.easyhealth.org.uk</a>
Easy read	Explaining about dementia	Cheshire and Wirral Partnership NHS Foundation Trust	<a href="http://www.easyhealth.org.uk">www.easyhealth.org.uk</a>
Easy read	Explaining about dementia	2gether NHS Foundation Trust and Picture of Health	<a href="http://www.apictureofhealth.southwest.nhs.uk">www.apictureofhealth.southwest.nhs.uk</a>

Easy read	Easy-read Older People's Mental Health Team leaflet	Derbyshire Community Foundation Trust	<a href="http://www.ldhealthnetwork.org.uk">www.ldhealthnetwork.org.uk</a> Case study on page 13 of this report.
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## Examples of Reasonable Adjustments and Case Studies

### **Raising awareness of learning disability and dementia in Bradford**

The Bradford Ageing Learning Disability and Dementia (BALDAD) group was formed to raise awareness and help meet the needs of people with learning disabilities and dementia.

In line with the Greenlight Tool—national guidelines about supporting people with learning disabilities to access mainstream mental health services wherever possible—BALDAD have agreed a pathway whereby people with mild learning disabilities access generic memory clinics. People with moderate to severe learning disabilities access the specialist learning disability pathway and learning disability memory clinic.

Terms of reference for the group, the learning disability/dementia pathway and Older Adults Interface model are available.

For further information please contact [Lesley.taylor@bdct.nhs.uk](mailto:Lesley.taylor@bdct.nhs.uk)

## Good practice in Derbyshire

Derbyshire Community Foundation NHS Trust have developed:-

- An integrated Mental Health and Learning Disabilities Service care pathway for people with dementia.
- A joint working pathway.
- A NICE guidance checklist.
- Learning disability training for staff working with older people including a questionnaire for new staff that determines their understanding of learning disabilities and dementia and their subsequent training requirements.  
<http://www.improvinghealthandlives.org.uk/adjustments/>
- Dementia training for learning disability staff.
- Accessible life stories folders adopted for all people using the service (not just those with learning disabilities).
- A link worker network for Learning Disability and Mental Health.

For further information please contact [gaynor.ward@derbshcft.nhs.uk](mailto:gaynor.ward@derbshcft.nhs.uk)

## Kent Community Healthcare Trust – small changes can make all the difference

Kent Community Healthcare Trust (KCHT) worked with a small service that was experiencing difficulties with people wishing to "wander about". The service adapted their small patio to make a raised walkway that wrapped around the entire building, enabling people to walk around safely without straying from the property.

KCHT are doing further work on a multidisciplinary team pathway and offering a baseline functioning assessment for people with Down's syndrome over 30 years. The mailshot leaflet should be available in July.

The dementia pathways were reviewed and amended so that people with learning disabilities could access the memory clinics in Older People Mental Health services where relevant, either independently or supported. Previously, people with learning disabilities had been excluded from this service.

A link to the dementia pathway can be found in the Resources section of this paper on page 12.

For further information contact [pene.stevens@kcht.nhs.uk](mailto:pene.stevens@kcht.nhs.uk)

## **MacIntyre Charity – Dementia Special Interest Group**

MacIntyre is a national charity that provides a wide range of services for children and adults with learning disabilities and autism.

Responding to the challenge posed by the changing needs of an ageing population, MacIntyre set up a Dementia Special Interest Group to bring together staff from across the organisation who were supporting people who had or were at risk of developing dementia to share best practice, provide peer support and find out about what was happening across the country.

It soon became clear that people were being very creative and person-centred in the support that was being provided and the most valuable part of the experience in bringing everyone together was the sharing of stories. The group captured many of these examples and compiled a booklet that is available to anyone who may find it useful. The booklet is updated with new tips and ideas each time the group meets.

A link to the Hot Tips booklet can be found in the Resources section of this report on page 13.

For further information contact [emma.killick@macintyrecharity.org](mailto:emma.killick@macintyrecharity.org)



## Designing a therapeutic environment in Greenwich

The Older Person's Service (TOPS) is a specialist day service provided by Oxleas NHS Foundation Trust and commissioned by the Royal Borough of Greenwich for older people who have a learning disability and a diagnosis of dementia.

The following is a list of changes which were made in the course of the refurbishment of two wards. The changes are in line with good practice around supporting people with dementia.

- Red crockery, i.e. cups & plates.
- Both male and female toilets have red toilet seats.
- Panic alarms in toilets are supported by photographic instructions.
- Vibrant red hand rails in main corridor.
- Brightly coloured card has been used on transport in order to distinguish and highlight certain steps.
- Day sessions, such as gardening, arts and crafts, relaxation etc. are graded in order to assess ability of users in attendance.
- A modified generic dementia baseline assessment for people with learning disabilities.
- Weekly assessment of people's wheelchairs and aids as deterioration can be very rapid around posture and seating.
- Regular referrals to speech and language therapy.
- Hand massage and aromatherapy sessions.
- The day service hosts a monthly aging issues clinic, which is supported by the multidisciplinary team and carers as well as people with learning disabilities, who are supported to attend and contribute.
- Twice-weekly reminiscence sessions run by an occupational therapist.

A pilot project is looking at producing one-minute DVDs of service users when they are first referred to the service, which, with their consent, can be used as a visual baseline. The DVD will be used when hospital admission is required so that hospital staff have an understanding of the person's functioning prior to becoming unwell, enabling them to understand what patients are capable of doing, so they can be supported accordingly.

For further information please contact [kaye.jones@oxleas.nhs.uk](mailto:kaye.jones@oxleas.nhs.uk)

## Manchester Learning Disability Partnership

Manchester Learning Disability Partnership has developed a number of tools and processes to support people with learning disabilities who have dementia:

- A series of top tip sheets for carers (family carers, support staff and whoever is working with/supporting people with dementia) regarding challenging behaviour, a suitable environment, eating and drinking issues, communication, personal care and maintaining skills (currently being evaluated).
- A baseline screening service for people with Down's syndrome before the age of 30. The assessments are repeated periodically.
- A multidisciplinary dementia and an interventions pathway.<sup>40</sup> Development of a screening project for people with Down's syndrome given the increased prevalence of early onset dementia. (*British Journal of Learning Disabilities*, 6(4), 18-26).
- Accessible information sheets about the assessment process for carers/people with learning disabilities.
- Multidisciplinary dementia interventions review process where everyone with dementia is reviewed every six-months by a multidisciplinary group. At this meeting a dementia interventions checklist is completed to ensure everyone has equal access to the dementia interventions available.
- Dementia awareness and dementia interventions training is provided regularly throughout the year for carers.
- A copy of the presentation made by Dr. Jervis in November 2012 (which provides more detail on the above) can be found at:  
[www.improvinghealthandlives.org.uk/adjustments/?adjustment=261](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=261)

For further information please contact [n.jervis@manchester.gov.uk](mailto:n.jervis@manchester.gov.uk)

## Surrey and Borders Partnership NHS Foundation Trust – Reasonable adjustments and people with learning disabilities and dementia

**Easy-read information:** Three booklets have been produced in association with BILD to help people with learning disabilities understand about getting older and dementia. *The Journey of Life* uses pictures and easy-read text to help the person understand the stages of life. Starting at birth, the book explains the life stages in the context of the amount of care a person may need at each of the stages. *About My Friend* uses pictures and easy-read text to help people with learning disabilities understand what happens to a friend when they develop dementia. Finally, *About Dementia* uses easy-read text to explain what dementia is, who gets dementia and what happens when you get dementia. See:

[www.bild.org.uk/our-services/books/health-and-well-being/the-journey-of-life/](http://www.bild.org.uk/our-services/books/health-and-well-being/the-journey-of-life/)

[www.bild.org.uk/our-services/books/health-and-well-being/about-my-friend/](http://www.bild.org.uk/our-services/books/health-and-well-being/about-my-friend/)

[www.bild.org.uk/our-services/books/health-and-well-being/about-dementia/](http://www.bild.org.uk/our-services/books/health-and-well-being/about-dementia/)

**Information for family and staff carers:** A number of resources have been developed to help staff and family carers understand about dementia and people with learning disabilities, and help people live well with dementia. Karen Dodd (Surrey and Borders Partnership NHS Foundation Trust) and Diana Kerr (University of Edinburgh) worked together with the Down's Syndrome Association to produce a Learning Disabilities and Dementia Workbook for staff and family carers. This book is a useful guide to help carers to offer the most effective care possible as the person's condition progresses and their needs change. Throughout the book there is signposting to other sources of information and resources as well as to various services which may be needed by the individual. Completion of the book leads to a more detailed understanding of the person, their situation and their individual needs. It also acts as a written record of the changing needs of the person and the actual actions that have been taken to ensure these needs are met. Karen Dodd and others have also worked with the Down's Syndrome Association to develop a number of DVDs to support families and staff carers.

[www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-professionals/1091-downs-syndrome-and-dementia-workbook.html](http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-professionals/1091-downs-syndrome-and-dementia-workbook.html)

[www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1087-downs-syndrome-and-dementia-philosophy-of-care.html](http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1087-downs-syndrome-and-dementia-philosophy-of-care.html)

[www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1086-downs-syndrome-and-dementia-forget-me-not.html](http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1086-downs-syndrome-and-dementia-forget-me-not.html)

[www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1085-downs-syndrome-and-dementia-fighting-for-andrew.html](http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-families/adults-18/1085-downs-syndrome-and-dementia-fighting-for-andrew.html)

For further information please contact [DrKaren.Dodd@sabp.nhs.uk](mailto:DrKaren.Dodd@sabp.nhs.uk)

## **Your Healthcare Community Interest Company (Surrey/South West London) – Reasonable adjustments to the environmental contexts for people with learning disabilities and dementia**

As part of our dementia care pathway, when someone with a learning disability is diagnosed with dementia, we complete an assessment of the living environment to try and assess which aspects of the environment are enabling and which may be potentially disabling, now or in the future, and give appropriate recommendations for reasonable adjustments to be made. The recommendations from the assessment are related to information covered in advanced training and this will enable carers to 'problem-solve' any future potential problems. We then produce a detailed report with clear recommendations about what is working well and what might need to change, and feed this back to the staff team, along with further written guidance about how environments can affect people with dementia.

The environmental assessments we complete are largely led by psychology. However, we plan to liaise with occupational therapy colleagues to develop the environmental aspects of our work with people with learning disabilities and dementia.

### *Clinical examples*

- A client who kept waking up in the night (day-night reversal) and wanting to go to the day centre found it difficult to believe that it was not time to go out when faced with waking night staff who were fully dressed, watching television telling him it was the middle of the night. We suggested to staff that they should have a dressing gown and pair of slippers they can put on when the client gets up, to help cue the client in to the verbal message that it is the middle of the night and not time to go to the day centre.
- Some clients find difficulty in moving between different coloured or textured thresholds, e.g. from a plain cream carpet in the living room to a complex, multi-coloured patterned carpet in the hallway. Therefore, we recommend that reasonable adjustments are made to carpets or floorings, such as having all one colour throughout the house and avoiding large patterned carpets because they can appear like holes or different depths to people with dementia. Carers have approached our team for advice about 'do's' and 'don'ts' before making changes to the environment such as redecorating or altering fixtures and fittings.

/Continued

- We often recommend that staff use red toilet seats and sometimes red tape to line the outer edges of the bath suite to enable people to continue to navigate and use the bathroom independently because some people may find it increasingly difficult to identify different features in the bathroom.
- With guidance from speech and language therapists, we often recommend that visual, olfactory and/or tactile indicators/cues are used to help clients identify different rooms around the house, particularly if clients have additional sensory impairments.
- We often recommend that furnishings are era-appropriate to fit with a person's long-term memory as it rolls back with the process of the dementia, often suggesting that staff make reasonable adjustments by purchasing furnishings and equipment that are familiar to the person.
- A major issue that sometimes cannot be changed about the environment is the layout of the building and location of bedrooms and accessible bathrooms. At all times, we try to make recommendations for reasonable adjustments to enable people with learning disabilities and dementia to stay in their own homes. However, due to lack of available space on the ground floor, and home structures that do not allow for other more major adjustments such as a lift, we may recommend that someone needs to move and make suggestions about what type of environment would be suitable. Alongside physiotherapy colleagues, we often request that reasonable adjustments such as track hoisting to be fitted.

For further information contact [Joanne.Coombs@yourhealthcare.org](mailto:Joanne.Coombs@yourhealthcare.org)

## Conclusion

People with learning disabilities are more likely to develop dementia than their non-disabled peers. Therefore it is important for public sector organisations to put reasonable adjustments in place so that people with learning disabilities continue to live fulfilling lives and can access dementia services effectively. This report signposts professionals, support workers and family carers to numerous resources that can be used to enable people with learning disabilities maintain quality of life and access dementia services. A number of examples of how these resources are being used have been included.

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