

# Supporting People with Learning Disabilities and Dementia

Practice Development Guide



# Supporting People with Learning Disabilities and Dementia

**A training pack for support staff (based on the *Supporting Derek* film and guide)**

© Karen Watchman, Heather Wilkinson and Philly Hare, 2018

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# Introduction

This practice development guide has been developed to support participants attending the training course *Supporting People with Learning Disabilities and Dementia*. (There is a separate and more detailed self-study guide for support staff and carers available that can be purchased at [www.pavpub.com/supporting-people-with-learning-disabilities-and-dementia/](http://www.pavpub.com/supporting-people-with-learning-disabilities-and-dementia/).)

The guide provides information on ten topics:

- ▶ Learning disability and dementia.
- ▶ Understanding behaviour.
- ▶ Developing supportive and meaningful environments.
- ▶ Responding to pain.
- ▶ Effective communication.
- ▶ Meaningful activities.
- ▶ When a friend has dementia.
- ▶ Eating and drinking.
- ▶ Night-time care.
- ▶ Advanced dementia.

In order to keep the training course of a manageable length (up to a full day), we have combined these topics into four training sessions.

The information in this guide will not only prepare you to get the most out of the course, but will be a reference to use during the training, along with thinking, self-reflection and practice activities. These can additionally be used as post-course opportunities for discussion with colleagues. The guide includes follow up reading for further study.

A link is provided to *Supporting Derek*, a short two-part film featuring actors with a learning disability that is used in the course. This will enable you to revisit some of the issues discussed during the course.

# Topic 1: Learning disability and dementia

The complexities of understanding how dementia is experienced by people with a learning disability, and lack of awareness of dementia as a possible diagnosis, mean that people with a learning disability are even less likely to receive a timely diagnosis than the population generally. A baseline assessment of current abilities before the onset of dementia is important as it offers a starting point from which significant and lasting change can be noted and measured. It is recommended that baseline assessments take place for all people with Down's syndrome from the age of 30, repeated every two years up to the age of 50 and every year after that.

It is important that dementia is understood as more than just loss of memory.

The most common changes to look out for in people with a learning disability are not obviously related to memory:

- ▶ Deterioration in daily living skills.
- ▶ Increased inactivity.
- ▶ Loss of interest in previously enjoyed activities.
- ▶ Reduced communication.
- ▶ New or increased confusion and/or disorientation.
- ▶ Changes in sleep pattern.
- ▶ Difficulty in perceiving depth, such as going up or down stairs or a roadside.
- ▶ Increased walking about without a clear reason.
- ▶ Changes to sight or hearing.

Remember, if a person has always shown such traits this is not indicative of dementia unless there is a change to typical behaviour pattern.

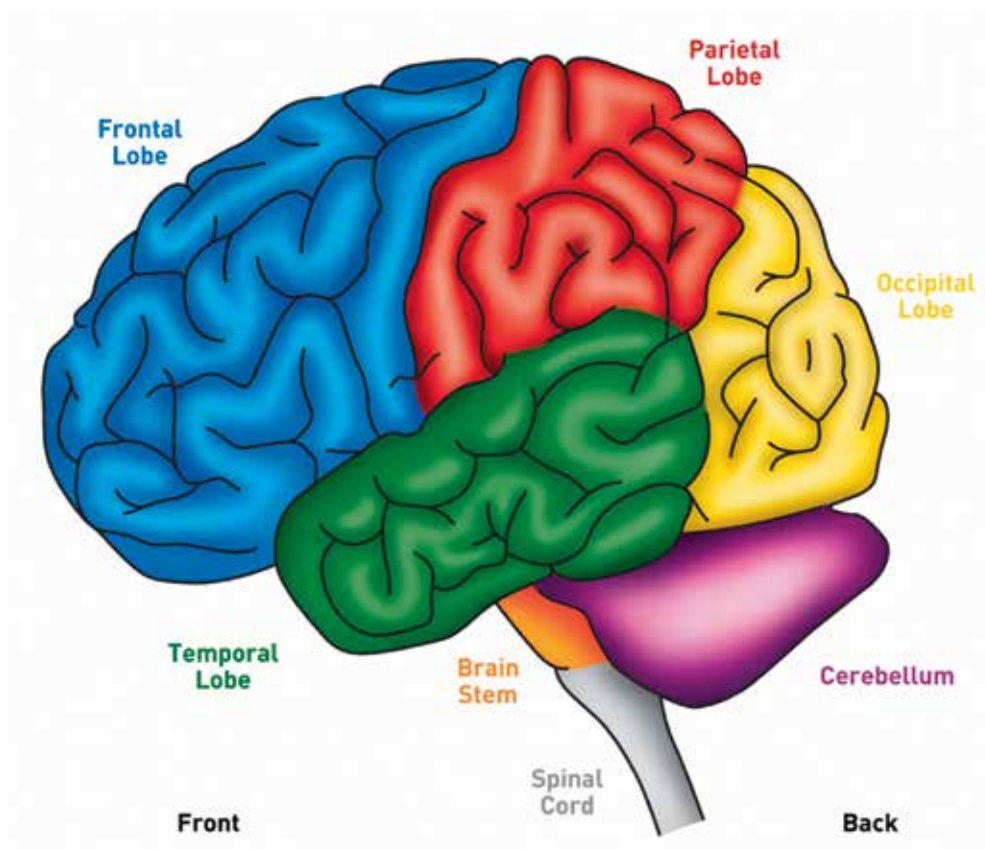
While many of the issues faced by people with dementia in the general population are the same for people with a learning disability, there are some additional points that those providing support need to be aware of:

- ▶ Diagnosis of dementia is harder and can take longer due to the communication difficulties that people may already have. This can lead to the belief that dementia progresses more quickly, whereas the delay in diagnosis is often a contributory factor.

- ▶ It is often assumed that the only type of dementia that people with Down's syndrome will get is Alzheimer's disease. Although people with Down's syndrome are most vulnerable to Alzheimer's disease, this does not mean that they do not develop other types of dementia as well, such as Lewy body dementia and frontal lobe dementia, or a combination of more than one type. Indeed, there may be a higher occurrence of frontal lobe dementia in people with Down's syndrome than previously thought, with frontal lobe changes being experienced from an early age.
- ▶ People with a learning disability (not Down's syndrome) can live with dementia for as many years as people without a learning disability. For people with Down's syndrome though, the progression to end stages and death is usually much quicker. This may, in part, be due to delay in diagnosis.
- ▶ While many people without a learning disability are supported by their partners or adult children, this is less common for people with a learning disability as they are more often single.
- ▶ As older parents may no longer be alive, siblings, friends, partners and previous carers play an important role in giving support, personal history and background information.

## Thinking activity

Look at the brain diagram and consider the changes in behaviour that may occur when different types of dementia are experienced.



Temporal lobe – stores verbal memory on the left and seeing, smelling and taste on the right. Both sides affect the ability to learn new things and retain short-term memory.

Parietal lobe – the right side helps us find our way around and understand where we are. Language and arithmetic skills are stored on the left along with the ability to understand our own bodies.

Frontal lobe – this is where new learning takes place before going to the parietal lobe. It is where we plan and motivate ourselves.

Occipital lobe – this is where we identify colour and recognise objects.

<b>Tool 1: Getting the right diagnosis</b>	
<b>Treatable conditions causing changes that can be confused with dementia</b>	<b>Changes that may indicate the onset of dementia</b>
<ul style="list-style-type: none"> <li>▶ Poor eyesight</li> <li>▶ Cornea inflammation</li> <li>▶ Hearing loss</li> <li>▶ Poor diet</li> <li>▶ Effects of medication</li> <li>▶ Recent bereavement</li> <li>▶ Significant change such as accommodation</li> <li>▶ Sleep apnoea</li> <li>▶ Early menopause in women with Down’s syndrome</li> <li>▶ Compulsive disorders</li> <li>▶ Cardiac abnormalities</li> <li>▶ Osteoporosis</li> <li>▶ Cataracts</li> <li>▶ Urinary tract infection</li> <li>▶ Joint pain</li> <li>▶ Change in sleep pattern</li> <li>▶ Depression</li> <li>▶ Diabetes</li> <li>▶ Hypothyroidism</li> <li>▶ Coning of the cornea</li> </ul>	<ul style="list-style-type: none"> <li>▶ Loss of road sense</li> <li>▶ Loss of interest in hobbies</li> <li>▶ Disorientation</li> <li>▶ New cognitive loss</li> <li>▶ Difficulty in finding the correct word</li> <li>▶ Difficulty with thresholds between rooms</li> <li>▶ Loss of daily living skills</li> <li>▶ Confused by steps or kerbs</li> <li>▶ Apathy</li> <li>▶ Attempting a task without realising it is not achievable</li> <li>▶ Not aware of having forgotten something</li> <li>▶ New short-term memory loss</li> <li>▶ Confusion</li> <li>▶ Loss of social skills</li> <li>▶ Deterioration in communication</li> </ul>

## Practice activity

Think back to a time in your past and remember how you felt at that time. Now imagine you are in the present day, but your recollection is of people and places from your past. Discuss how this may make you feel and which aspects of your life would not make sense to you.

## Key points

It is important to be able to recognise the early signs of dementia in people with a learning disability and to know where to go for support and diagnosis. But we must not jump to conclusions and assume that a person has dementia when their condition may be caused by something else that is treatable. If a diagnosis of dementia is made, there are lots of ways in which the right support can lead to positive experiences.

## Further reading

BILD Easy Read Factsheets: <http://www.bild.org.uk/resources/ageingwell/dementiafactsheets/> (accessed September 2018).

DEEP (The UK Network of Dementia Voices) <http://dementivoices.org.uk/> (accessed September 2018).

Dodd K, Watchman K, Janicki M, Coppus A, Gaertner C & Fortea J (2017) Consensus statement of the international summit on intellectual disability and dementia related to post diagnostic support. *Aging & Mental Health*. Epub ahead of print.

National Down Syndrome Society (2018) *Alzheimer's Disease and Down Syndrome* [online]. Available at: [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf) (accessed September 2018).

National Task Group on Intellectual Disabilities and Dementia Practices (NTG) NTG-EDSD Screening Instrument. Available at: <http://aadmd.org/ntg/screening> (accessed September 2018).

Public Health England (2018) *Dementia and People with Learning Disabilities* [online]. Available at: <https://www.gov.uk/government/publications/people-with-dementia-and-learning-disabilities-reasonable-adjustments/dementia-and-people-with-learning-disabilities> (accessed September 2018).

Watchman K. Learning Disability and Dementia International Summit Reports: <http://www.learningdisabilityanddementia.org/id-dementia-summit.html>

Watchman K (2017) *Intellectual Disabilities and Dementia. A guide for families*. London: Jessica Kingsley Publishers.

Watchman K & Strydom A (2018) Learning Disabilities and Dementia: Alzheimer's Society factsheet 430.



# Topic 2: Understanding behaviour

When someone has dementia, we may at times find their behaviour unusual or difficult. There is always a reason for a person having altered behaviour and we need to find out what it is – sometimes we ourselves are the cause.

## Reasons for changed behaviour

Potential reasons for changes in behaviour in a person with dementia may include:

- ▶ an environment that is too confusing or noisy
- ▶ changes in communication
- ▶ mixing up day and night
- ▶ not recognising own reflection in mirrors
- ▶ not being able to eat without support, but being unable to express this appropriately
- ▶ forgetting where the bathroom is
- ▶ not having pain detected or treated
- ▶ not remembering where 'home' is, but needing to look for it
- ▶ not recognising current carers or friends, but looking for family or familiar people who may have died many years ago
- ▶ remembering routines from when the person was younger, but not from recent months or years
- ▶ the effect of poor lighting and the design of the building
- ▶ boredom resulting from lack of stimulating activity.

## Supporting changed behaviour

### Approaches to behaviour

When we try to understand someone's behaviour it is important to consider that there may be more than one reason for that behaviour and that we may need to try different approaches:

- ▶ Making sure that medication is not used as a first response.
- ▶ Finding out what has triggered the behaviour; what happened immediately before and what happened as a result.

- ▶ Trying to understand what the person needs or wants to communicate to us.
- ▶ Looking from the perspective of the person who has dementia; remembering that they are likely to be disorientated, frightened and confused.
- ▶ Altering our verbal communication methods.
- ▶ Altering our non-verbal communication methods.
- ▶ Using gentle touch.
- ▶ Using calming music if the person likes this.
- ▶ Providing an activity that the person enjoys, or other distraction.

## Thinking activity

Think about the behaviour you find difficult in the person you support. Try to put yourself in the shoes of the person with a learning disability and dementia to look for an explanation. Consider the building you are in, how you approach the person, what time of day (or night) it is and who else is present.

### Tool 2A: Understanding behaviour

- ▶ Is the environment too confusing or noisy?
- ▶ Are instructions clear and short?
- ▶ Are there visual prompts to remind the person if it is day time or night time?
- ▶ Is appropriate support given at meal times?
- ▶ Is it clear which door the toilet is behind?
- ▶ Could the person be in pain?
- ▶ Do you know where they think of as 'home'?
- ▶ Are you familiar with activities and routines from when the person was younger?
- ▶ Is the lighting and design appropriate for people with dementia?
- ▶ Who does the person look for when they are seeking familiar faces and what was the nature of their relationship?
- ▶ Is there enough choice over activities that are both stimulating and meaningful for the individual?

**What happened before the behaviour?**

**Who else was there?**

**When did it happen?**

**Where did it happen?**

**What exact behaviour occurred?**

**What happened afterwards?**

## Tool 2B: Dealing effectively with changing behaviour

### DO:

- ▶ stay calm
- ▶ use a calm voice
- ▶ touch the person gently, making sure they have seen you first
- ▶ turn off any music that has an agitating beat or high noise level
- ▶ use gentle, calming music
- ▶ give the person room to move or walk away
- ▶ offer reassurance
- ▶ try to divert attention.

### DO NOT:

- ▶ confront the person
- ▶ shout or raise your voice
- ▶ say that a family member is dead, even if they are
- ▶ tease or make fun of someone
- ▶ invade their personal space
- ▶ move quickly, especially from behind
- ▶ corner the person.

Adrenalin stays in the body for up to 90 minutes. Even if a person has calmed down, this means that they may still be agitated or ready to display difficult behaviour again quickly. Try to keep the environment as calm as possible to prevent this from happening.

## Practice activity

Discuss how you would feel, or what you would do, if a stranger came into your home and started looking through your fridge and removing food.

## Key points

How we respond to a person's behaviour is a central part of the care and support of a person with a learning disability and dementia. Consider what you know of the person's wishes and preferences as this will inform your understanding of their behaviour. There may be gaps in your knowledge – strategies and supports suggested in this summary guide will help to address this and to understand what a positive outcome looks like for the person you support.

## Further reading

Alzheimer's Society (2014) *Factsheet 525LP: Changes in Behaviour* [online]. London: Alzheimer's Society. Available at: [https://www.alzheimers.org.uk/download/downloads/id/3354/changes\\_in\\_behaviour.pdf](https://www.alzheimers.org.uk/download/downloads/id/3354/changes_in_behaviour.pdf) (accessed September 2018).

British Psychological Society (2015) *Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia* [online]. Leicester, UK: The British Psychological Society. Available at: [https://www1.bps.org.uk/system/files/Public%20files/rep77\\_dementia\\_and\\_id.pdf](https://www1.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf) (accessed September 2018).

Iacono T, Bigby C, Carling-Jenkins R & Torr J (2014) Taking each day as it comes: Staff experiences of supporting people with Down's syndrome and Alzheimer's disease in group homes. *Journal of Intellectual Disability Research* **58** (6) 521–533.

Jokinen N, Gomiero T, Hogan M, Larsen F, Berankova A, Santos F, Watchman K, Janicki M & Crowe J (2018) Challenges and perspectives in the caregiving of ageing people with intellectual disability affected by dementia: commentary from the International Summit on Intellectual Disability and Dementia. *Journal of Gerontological Social Work* **61** (4) 411–431.

Strydom A, Al-Janabi T, Houston M & Ridley J (2016) Best practice in caring for adults with dementia and learning disabilities. *Nursing Standard* **31** (6) 42–51.

# Topic 3: Developing supportive and meaningful environments

We are all influenced by our environment, but people with dementia can be more affected. The room size, heat level, arrangement and type of furniture, air quality, lighting and noise level will all have an impact on the way we work, live and relax. While we have a certain amount of control over these aspects of the environment, a person with dementia often does not. This is particularly problematic because the changes brought about by dementia mean that the environment can feel increasingly unpredictable, unfamiliar and distressing.

The increasing impairment associated with dementia means that people become more dependent on the structure of their environment to help them cope. They also become much more sensitive to their social, emotional and physical environment. It is not surprising, therefore, that much of the behaviour we see amongst people with dementia is caused by the ways carers communicate and by the environment.

Making suitable adaptations to the environment someone lives in can reduce distress and behaviour that we, and they, may find difficult. However, there are advantages and disadvantages to changing the environment, and some changes may be too confusing if not implemented early enough. Many people with a learning disability share a home with others, whether family or friends, and the impact of any environmental changes should be considered on everyone.

Changes can be made in residential and family homes, and in community facilities, including GP surgeries and hospitals. Remember that what works for one person will not necessarily work for others. If one strategy does not work we need to keep trying, rather than thinking that nothing can be done. Changes will not be permanent so strategies for support should also not be viewed as permanent – what works now may not work in a month's time for example so should be regularly reviewed.

## Thinking activity

Think about the signs in your workplace or signs that you have seen elsewhere. Think about the style, height, how appropriate they are and what may need to be changed as the needs of people with a learning disability change.

### Tool 3: Developing a supportive environment

Person's name \_\_\_\_\_

#### What would make their environment ...

##### Calm

What are the barriers to this?

\_\_\_\_\_

How can these be overcome?

\_\_\_\_\_

##### Suitably stimulating

What are the barriers to this?

\_\_\_\_\_

How can these be overcome?

\_\_\_\_\_

##### Predictable

What are the barriers to this?

\_\_\_\_\_

How can these be overcome?

\_\_\_\_\_

##### Make sense

What are the barriers to this?

\_\_\_\_\_

How can these be overcome?

\_\_\_\_\_

##### Familiar

What are the barriers to this?

\_\_\_\_\_

How might these be overcome?

\_\_\_\_\_

##### Action to be taken

\_\_\_\_\_

Person(s) responsible \_\_\_\_\_

Date for next review \_\_\_\_\_

## Practice activity

Complete the 'Is this inside/outside public space dementia-inclusive' checklists (Resource 2.1 and 2.2)

## Key point

Attention should be paid to the physical environment of the person with dementia. This includes where each person lives and socialises. Whilst respecting individual preferences, the environment should be calm, familiar, predictable, make sense and be appropriately stimulating.

## Further reading

National Task Group on Intellectual Disabilities and Dementia Practices (2012) *'My Thinker's Not Working': A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality support* [online]. Available at: [https://aadmd.org/sites/default/files/NTG\\_Thinker\\_Report.pdf](https://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf) (accessed September 2018).

Forbat L & Wilkinson H (2008) Where should people with dementia live? Using the views of service users to inform models of care. *British Journal of Learning Disabilities* **36** (1) 6–12.

Watchman K (2006) *Living with Dementia: Adapting the home of a person who has Down's syndrome and dementia – a guide for carers* [online]. Edinburgh: Down's Syndrome Scotland. Available at: <http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/living-with-dementia.pdf> (accessed September 2018).

Wilkinson H, Kerr D & Rae C (2004) *Home for Good?* [online]. York: The Joseph Rowntree Foundation. Available at: <https://www.winnserv.ca/DEMENTIA%20PDF/Home%20for%20Good.pdf> (accessed June 2018).

# Topic 4: Responding to pain

As people get older, they are more likely to experience pain, particularly chronic pain. People with dementia may find it hard to tell others when they are in pain, where this is and how bad it is. Therefore it is important that we are aware of this and are able to provide appropriate responses. Take the time to understand how individuals with a learning disability and dementia experience pain, how they express this and how we can anticipate it. It is a myth that people with a learning disability, including people with Down's syndrome, do not feel pain, or have a high pain threshold. It is how this pain is communicated that may differ.

Similarly, people with dementia may appear to tolerate or not recognise pain. This does not mean that they are not suffering; it may just mean that their pain has to worsen before anyone realises. Pain detection is made difficult by:

- ▶ loss of vocabulary and difficulty finding the right words to express pain
- ▶ a lack of understanding about how the body works.

People with dementia may lose the cognitive skills to remember left from right and confuse parts of the body even if they know the correct general area. For example, the mouth may be confused with the eyes or the abdomen may be confused with the chest. As a result, the person may find it difficult to identify the part of their body that hurts. So, if they have a toothache they might not be able to find the word to express this and may also be unable to indicate where the pain is. Or they may point out that someone else is in pain, when in fact it is them.

## Thinking activity

Consider different types of pain that you feel, the words that you use to describe it, how it makes you feel and what treatment you seek.



### Tool 4: Pain detection

Pain is often ignored or mistaken for behavioural problems



Common causes of chronic or acute pain that often untreated and unrecognised:

- ▶ joint pain
- ▶ urinary tract infection
- ▶ painful gums or teeth
- ▶ constipation
- ▶ impacted ear wax
- ▶ eye infection
- ▶ cellulitis
- ▶ arthritis.

## Practice activity

Think of a person you support who has a learning disability and dementia. Discuss the verbal and non-verbal signs of pain that they show and the reaction of staff to this.

## Further reading

Abbey J, De Bellis A, Pillar N, Esterman A, Giles, L, Parker D & Lowcay D (2002) *Abbey Pain Scale*. Adelaide: JH and JD Gunn Medical Research Foundation. Available at: [http://prc.coh.org/PainNOA/Abbey\\_Tool.pdf](http://prc.coh.org/PainNOA/Abbey_Tool.pdf) (accessed September 2018).

Joseph Rowntree Foundation Findings (2006) *Pain Management for Older People with Learning Difficulties and Dementia*. Available at: <https://www.jrf.org.uk/report/pain-management-older-people-learning-difficulties-and-dementia> (accessed September 2018).

Massachusetts General Hospital (2004) *Pain Assessment in Advanced Dementia (PAINAD) Tool Guidelines*. Massachusetts: Massachusetts General Hospital. Available at: <http://geriatrictoolkit.missouri.edu/cog/painad.pdf> (accessed September 2018).

Northumberland Tyne and Wear NHS Trust & St. Oswald's Hospice (2008) *Disability Distress Assessment Tool. DisDAT*. Available at: [http://prc.coh.org/PainNOA/Dis%20DAT\\_Tool.pdf](http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf) (accessed September 2018).

Posters and factsheets available free to download from the above Joseph Rowntree Foundation website. Available at: <https://www.jrf.org.uk/report/do-you-recognise-pain-someone-learning-difficulty-and-dementia> (accessed September 2018).

## Key point

Knowing that people with a learning disability and dementia will experience high levels of unrecognised and untreated pain should make us much more pro-active in the support that we provide.

# Topic 5: Effective communication

A person's ability to communicate verbally will change as dementia progresses. Such changes do not mean that the person is not able to communicate at all. A two-way conversation may not be possible, but meaningful communication is still both possible and essential. As dementia progresses, new communication methods must be sought and maintained. It is important that we do not give up trying to communicate. This is especially important if a change in accommodation has taken place, as new carers must understand the preferred communication method and ensure all other staff are aware.

People with dementia still want to communicate and they increasingly do so through their behaviour. We should focus on supporting people to maintain their interests for as long as possible and maximise our use of non-verbal communication. Having an understanding and knowledge of the person before their diagnosis of dementia will help, as will spending time with them to 'tune in to' their current communication. It will be helpful to keep the staff group supporting the person as small as possible, so there is greater familiarity and consistency in interactions.

It is important to be aware of, and monitor, any sensory changes that the person is experiencing as this can impact on communication. For example, hearing loss can affect many people with Down's syndrome. This may be as a result of increased incidence of chronic ear disease or differences in the structure of the ear. Not responding to requests or conversation may be misinterpreted as an early sign of dementia when in reality a hearing check can resolve this issue.

Some ways in which we can support a person with dementia to communicate, both verbally and non-verbally, include:

- ▶ Turn towards the person when speaking and maintain eye contact.
- ▶ Smile when speaking.
- ▶ Use a friendly tone of voice (sometimes the person with dementia will hear only the tone rather than what is actually said).
- ▶ Use short sentences.
- ▶ Do not speak to anyone else at the same time.
- ▶ Speak in the same language that the person uses and understands.
- ▶ Do not give more than one message or request in one sentence.
- ▶ Do not touch the person from behind without being seen, as this may cause alarm.

- ▶ Do not be embarrassed by silences (silences do not necessarily mean that the person has not understood). Often a person with dementia will make an appropriate response to a conversation many minutes later after a prolonged period of silence.
- ▶ Talk to the person at the same eye level or lower rather than looking down on them, as this may seem threatening.
- ▶ Make sure that the room or environment is quiet.

## Thinking activity

Think about directional statements or typical requests that you may frequently make. Break down the statements to work out how many requests are in each one and how each may be misunderstood or bring about a different reaction from the person with a learning disability and dementia.

<b>Tool 5: Verbal and non-verbal cues</b>	
<b>Verbal and non-verbal changes in communication that may occur</b>	<b>Suggestions for verbal and non-verbal communication</b>
<ul style="list-style-type: none"> <li>▶ Difficulty in finding the right word</li> <li>▶ Unusual speech pattern</li> <li>▶ Repeating words</li> <li>▶ Changing pronunciation of words</li> <li>▶ Increase in shouting</li> <li>▶ Forgetting recently learned information</li> <li>▶ Makaton signs</li> <li>▶ Becoming flustered</li> <li>▶ Picking at skin</li> <li>▶ Becoming more upset</li> <li>▶ Losing track of a conversation</li> <li>▶ Constantly talking more or less</li> <li>▶ Wringing of hands</li> </ul>	<ul style="list-style-type: none"> <li>▶ Make eye contact</li> <li>▶ Smile while speaking</li> <li>▶ Use a friendly tone of voice</li> <li>▶ Use short sentences</li> <li>▶ Speak in the same language as the person with dementia</li> <li>▶ Do not be afraid of silence, this can be thinking time</li> <li>▶ Do not give too many messages at the same time</li> <li>▶ Do not use defensive or aggressive body language</li> <li>▶ Talk to someone at their eye level</li> <li>▶ Make sure the room is quiet</li> <li>▶ Do not speak to anyone else at the same time</li> <li>▶ Do not touch the person from behind</li> </ul>
<p><b>People with dementia still want and need to communicate.</b></p> <p><b>To support this we must pick up on and return their cues.</b></p> <p><b>Remember, a large part of our communication is non-verbal.</b></p>	

## Practice activity

Discuss what happens in your work setting on a daily basis and the noise this may create.

## Key point

Even though people with a learning disability are likely to have had an existing communication disability, we still need to develop new strategies and ways of understanding after a diagnosis of dementia.

## Further reading

Alzheimer's Society (2015) *Communicating and Language* [online]. Available at: <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/communicating-and-language> (accessed September 2018).

Bradshaw J (2013) *Communication and Challenging Behaviour – information sheet* [online]. Available at: <http://www.challengingbehaviour.org.uk/learning-disability-files/04---Communication-Information-sheet-web.pdf> (accessed September 2018).

Royal College of Speech and Language Therapists (2013) *Five Good Communication Standards* [online]. Available at: [https://www.rcslt.org/news/docs/good\\_comm\\_standards](https://www.rcslt.org/news/docs/good_comm_standards) (accessed September 2018).

Talking Mats® have developed a range of resources to support staff and families working with people with communication disability: [www.talkingmats.com](http://www.talkingmats.com)

The Dementia Engagement and Empowerment Project (DEEP) (2014) *Dementia Words Matter: Guidelines on language about dementia* [online]. Available at: <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf> (accessed September 2018).

# Topic 6: Meaningful activities

People with dementia will become noticeably less able to start activities for themselves, although they may still want to do so. As a result, they may become increasingly bored or frustrated, which can lead to behaviour that we find difficult. We can support people to take part in activities they find easier, that are appropriate to their abilities and which can help to maintain skills or social relationships. This means that the activities must be:

- ▶ failure free, so that the person can feel they are accomplishing something without the fear or embarrassment of making mistakes
- ▶ enjoyable
- ▶ uncomplicated
- ▶ tailored to individuals.

Pressure should not be placed on someone to move from room-to-room, for example in a day or resource centre, to take part in different activities. This, along with the confusion and the noise of a number of people moving around at the same time, can prove stressful for people with dementia.

Where possible, the activity should go to the person, so that they can continue it if they are enjoying it, rather than feeling pressure to change activities because others do. We should not be prescriptive about the kind of activities that people are invited to join in with, as preferences will vary. Such interventions can increase the sense of wellbeing among people with dementia and may include:

- ▶ Group or individual reminiscence activities.
- ▶ Life story work.
- ▶ Craft or art.
- ▶ One-to-one and group discussions and conversations.
- ▶ Domestic tasks, which often prove to be more enjoyable than more formal and structured activities, as they remind people of what they did when they were younger, and reinforce that they still have skills to contribute.
- ▶ Music playlists. Using an MP3 player can be more accessible, does not require an online account and allows for individualised preferences, although not everyone may be comfortable using headphones.

While following familiar rules can help some, this may eventually become problematic. As dementia progresses, activities should be repetitive and require minimal instruction. Use caution, as an effective and successful intervention for one person may be less positive or even distressing for another. For example, do not

assume that everyone will benefit from reminiscence activities, especially if negative memories are recollected.

For an activity to be meaningful there may be a link to something that the person enjoys or enjoyed doing. Meaningful activity can include being able to look at the garden, which should ideally contain plants, birds, ornaments or animals – even a washing-line – if appropriate, as well as safe areas for walking and sitting. Making use of outdoor areas can aid well-being and health. Some people may enjoy community outdoor activities, walking, sports or visiting places of interest. Outdoor activities will have the additional benefit of boosting vitamin D levels.

## Thinking activity

Think about your early memories and what you would like others to know about you in the future.

### Tool 6: Life story work: helping you learn the 'reality' of the person you support

Do you know:

- ▶ the person's background – where they grew up and who with?
- ▶ what they liked to do when they were younger?
- ▶ their favourite food and drink?
- ▶ food and drink they do not like?
- ▶ if they like to sing and, if so, what songs?
- ▶ what activities or responsibilities they enjoyed when younger?
- ▶ the sounds or smells that may cause upset or may provoke happy memories?
- ▶ if there is contact with family?
- ▶ what type of dementia the person has?
- ▶ what the person says if they are upset or in pain?
- ▶ what non-verbal clues the person gives if they are upset or in pain?
- ▶ how the person communicated before they had dementia?
- ▶ if life-story work has been started and, if so, where it is kept?
- ▶ who will discuss end-of-life care and in what way?
- ▶ what the person has been told about the changes they are experiencing and the words that were used to explain this?

**Knowing all of this will help you know the reality of the person you are supporting and enable you to plan with them for their future.**

## Practice activity

Discuss the approach that your organisation has towards life story work. Is there a process of gathering background information, with permission, before a person moves in or uses the service? If not, consider what this may look like and how carers and people with a learning disability and dementia may be involved. If it exists, discuss how often it is updated and how the process may be improved.

## Key point

Despite the changes and cognitive losses that accompany dementia, there are many failure-free activities and interventions that can help someone maintain their quality of life for longer.

## Further reading

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Kiddle H, Drew N, Crabbe P & Wigmore J (2016) A pilot memory cafe for people with learning disabilities and memory difficulties. *British Journal of Learning Disabilities* **44** (3) 175–181.

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Shivers C, McCarron M, McCallion P & Dinsmore J (2014) Acceptability of a multimedia life stories platform in a residential home for individuals with dementia and intellectual disability [online]. *Journal of Applied Research in Intellectual Disabilities* **27** (4) 397–398. Available at: [http://iassidd2014.univie.ac.at/uploads/media/Shivers-Acceptability\\_of\\_a\\_multimedia\\_life\\_stories\\_plattform\\_in\\_a\\_residential\\_home.pdf](http://iassidd2014.univie.ac.at/uploads/media/Shivers-Acceptability_of_a_multimedia_life_stories_plattform_in_a_residential_home.pdf) (accessed September 2018).

Ward A & Parkes J (2017) An evaluation of a Singing for the Brain pilot with people with a learning disability and memory problems or a dementia. *Dementia* **16** (3) 360–374.



# Topic 7: When a friend has dementia

Friendships and social relationships are important to us all. For a person with a learning disability and dementia, relationships may include:

- ▶ long-term friends whose expertise may come from years of knowing and supporting the person
- ▶ peers with a learning disability (and possibly dementia too), in a shared group home
- ▶ peers in other contexts such as self-advocacy groups
- ▶ colleagues in paid or voluntary work settings
- ▶ formal carers, staff and volunteers who are often the most constant person in the lives of some people with learning disabilities.

Support provided by staff for friends of a person with a learning disability and dementia can take many different forms:

- ▶ Sharing appropriate information about health changes in a way that is clear and non-medical.
- ▶ Explaining that their relationships will change, and that this is not anyone's fault.
- ▶ Reinforcing the continued importance of friendships.
- ▶ Explaining why the person with dementia may not always recognise others.
- ▶ Assisting with acknowledging and understanding the changing behaviour in their friend.
- ▶ Helping to understand the impact that their behaviour will have on the person with dementia; their responses can be supportive and reassuring, or increase feelings of confusion in the person with dementia.
- ▶ Provision of one-to-one or group training and support sessions, using accessible, pictorial/Easy Read information about dementia to build on any knowledge that they may already have, for example *Jenny's Diary* (see further reading).
- ▶ Explaining why staff need to spend more time with the person who has dementia.
- ▶ Addressing the concerns of peers who may worry that they, or other friends and family, will also develop dementia
- ▶ Explaining why their friend's behavior is changing and why they are becoming more introverted or detached; less inhibited; or less willing to go out.
- ▶ Continuing to celebrate birthdays and religious festivals for the person who has dementia. The celebrations may need to be quieter and less active than previous years, but should still involve friends and family.

## Thinking activity

Think about how much information or explanation you would want to know about your health as you age. Would you want the same information about a family member or friend?

### Tool 7: Top tips for supporting a friend or family member

When a person with a learning difficulty has a friend or family member with dementia it is important to:

- ▶ talk about the changing behaviour of their friend or family member
- ▶ find out what they already know about dementia – they may have had previous exposure to the condition
- ▶ clarify that the person is not behaving this way on purpose
- ▶ explain that the person with dementia may not recognise their friends in the future
- ▶ help them understand that their behaviour can prompt increased confusion when someone has dementia
- ▶ assist them to maintain their friendship should the person with dementia need to move accommodation or have a short stay in hospital
- ▶ reassure those who may worry that they will also get dementia and may want to talk about this
- ▶ explain why staff may need to spend more time with the person who has dementia
- ▶ plan one-to-one or group sessions which use easy-to-understand pictorial information to explain what dementia means
- ▶ understand the amount of background information that friends can give when putting together life-story information.

## Practice activity

Discuss how much the people with a learning disability you support may already know about dementia, possibly as a result of previous experience among friends or family. If this is not known, how will you find out?

## Key point

Training and support is rarely considered for the friends of people with a learning disability and dementia, yet it is often peers who spend the most time with the person.

## Further reading

Foundation for People with Learning Disability (2015) *Talking Together: Facilitating peer support activities to help people with learning disabilities understand about growing older and living with dementia*. Available at: <https://www.mentalhealth.org.uk/learning-disabilities/publications/talking-together> (accessed September 2018).

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Watchman K, Tuffrey-Wijne I & Quinn S (2015) *Jenny's Diary: Supporting conversations about dementia with people who have a learning disability* [online]. London: Alzheimer's Society. Available at: <http://www.learningdisabilityanddementia.org/jennys-diary.html> (accessed September 2018).

# Topic 8: Eating and drinking

Everyone needs to eat and drink well to maintain good health, including people with dementia. However, it may become increasingly difficult to eat and drink well, enjoy food and drink, and get pleasure from the social interaction associated with meal times. This is because:

- ▶ their sense of smell and taste will continually change as dementia progresses – food that was previously enjoyed can taste bland and be unappealing, so they may start to eat food they have not liked before or develop cravings for different food, especially sweet things
- ▶ they may forget that they have just eaten, or save food to eat later
- ▶ they may not recognise when they are feeling hungry or thirsty
- ▶ they may forget what to do once food is in their mouth
- ▶ toothache or painful false teeth may prevent eating, although the person may not be able to explain this
- ▶ it may be difficult to recognise cutlery and crockery or remember how to use them to eat and drink, even if the person is thirsty or hungry.

## Help at meal times

People with dementia can be supported at meal times in the following ways:

- ▶ Reduce distracting noise levels at meal times and avoid speaking over a person to someone else.
- ▶ Only offer food and drink the person likes.
- ▶ Cut the food into small, easily manageable pieces.
- ▶ If the person is not eating much, ensure that what they do eat is fresh and healthy and of maximum benefit to them.
- ▶ Try to find out how the person prefers to eat meals (e.g. sitting at a table or eating from a tray on their lap, alone or in a group).
- ▶ Ensure the person is sitting correctly to reduce the chance of choking, which is more likely to occur as the muscles used for swallowing become weaker.
- ▶ Try to find out if the person likes a drink with their meal or afterwards and what their preferred drink is.
- ▶ Sit and eat with the person to help provide cues and make the meal a more social opportunity.

- ▶ Use contrasting colour on the table – the plates should contrast with the table covering and, ideally, the food should contrast with the plate.
- ▶ Too much pattern can cause confusion and prevent the person enjoying meal times, as they may confuse the pattern with food.
- ▶ Use cutlery and cups that help the person to eat and drink. This will change depending on the stage of dementia.
- ▶ Describing what the food is, what it looks like and what it tastes like can help if the person is also visually impaired.
- ▶ If food needs to be blended, it is important to keep different types of food separate so that the different flavours can still be recognised even if the food looks different.
- ▶ Leave small snacks around (regularly replaced), perhaps along the route the person tends to walk regularly.

## Thinking activity

Consider the local professionals who are involved in providing additional support at mealtimes. Who else should be involved and at what stage?

### Tool 8A: Support at meal times

Plates have too much pattern and are lost on



Heavily patterned napkins



Tablecloth looks as if pieces can be picked off it

Salt and pepper pots are too modern

Mugs may not be recognised

Contrast between plate and mat or table



Individual attention should be given when eating



No strong patterns on the table

Make use of what you have and what the person knew in their past

Sauce bottles may be age

Meal times should be as quiet as possible

### Tool 8B: Guidelines for helping people to eat well

- ▶ Make sure the environment is calm and quiet.
- ▶ Make sure there are regular intervals between meal times.
- ▶ Tables should not be set more than 30 minutes before eating.
- ▶ Meals should be served one course at a time.
- ▶ Finger food should be available if needed and regularly replaced.
- ▶ Staff should be present and involved at meal times.
- ▶ The same carer should stay with the person during a meal.
- ▶ Carers should not speak over the person who is being supported to eat.
- ▶ The correct glasses should be worn and they should be clean.
- ▶ Make sure the person is sitting upright and supported, to reduce the chance of choking.
- ▶ Small mouthfuls should be encouraged.
- ▶ Allow time for the person to swallow.
- ▶ Give clear verbal prompts.
- ▶ Offer the choice of a cup or mug, soft drink or water, tea or coffee.
- ▶ Help, but do not force.
- ▶ Sit at the person's eye level or just below, in front or slightly to the side.
- ▶ Use cutlery and cups that are adapted to the person's changing abilities.

## Key point

New ways of supporting people at meal times will be needed to avoid dehydration and malnutrition. Try to maintain the person's involvement in the social aspects of meal times.

## Further reading

Alzheimer's Society (2016) *Eating and Drinking, Factsheet 511LP* [online]. Available at: <https://www.alzheimers.org.uk/get-support/daily-living/eating-drinking> (accessed September 2018).

Dementia UK (2018) *Eating and Drinking for People with Dementia* [online]. Available at: <https://www.dementiauk.org/understanding-dementia/advice-and-information/maintaining-health-in-dementia/eating-and-drinking/> (accessed September 2018).

# Topic 9: Night-time care

Finding a way to manage a person's sleep problems can make a real difference to the stress levels of staff and families, and of course those of the person with a learning disability and dementia themselves.

## Sleep disruptions

Changes to night-time sleep caused by the onset of dementia can include:

- ▶ night terrors
- ▶ sleep talking
- ▶ sleep walking
- ▶ 'acting out' dreams
- ▶ enuresis (incontinence at night)
- ▶ night-time waking
- ▶ pain
- ▶ nocturnal seizures (as dementia progresses).

These are due to changes in the brain that can happen with dementia. Such changes can bring about sleepiness, poor co-ordination, short temper or aggression, poor memory during the day and even hallucinations if sleep becomes very disrupted.

The body clock of a person with dementia can become increasingly disturbed and they will wake more often at night. However, they may not be aware that it is night time and may try to start their day by getting dressed or having breakfast, even if it is 4am.

Waking at night time needs to be addressed for a range of reasons:

- ▶ To reduce the possibility of others being disturbed, if the person lives in shared accommodation.
- ▶ To avoid the use of excessive night-time sedation.
- ▶ To keep the person in their own accommodation.
- ▶ To manage staff stress levels, and the effects that this in turn would have on residents.
- ▶ Consider your own actions at night-time; for example, try not to speak loudly, walk noisily, have music or the television turned on or carry out noisy household activities. Bright lights can indicate daylight and should be avoided.

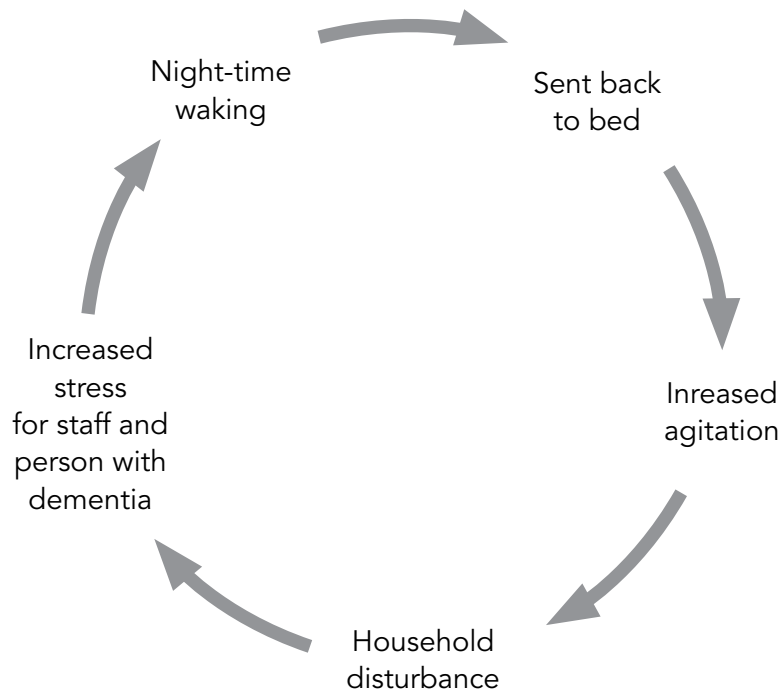


## Thinking activity

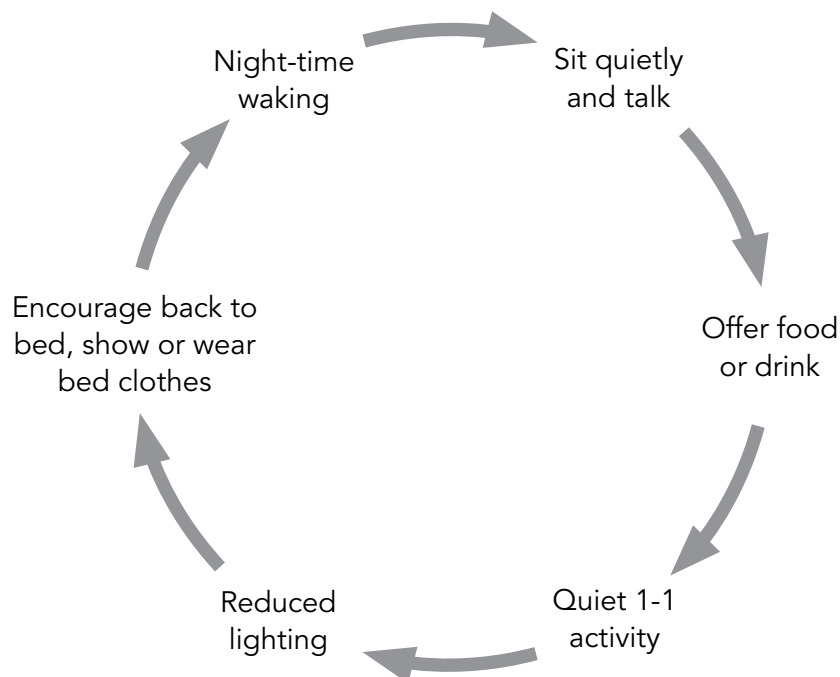
Think about how you feel when your sleep pattern is disrupted. What time of day is the quietest in your house and provides you with time to yourself. How do you feel if this is interrupted?

### Tool 9: Night-time waking – know the cycle

Too often we see the following night-time cycle:



Night-time waking can be used as an opportunity:



## Practice activity

If you work in a residential setting, discuss the guidance available to staff providing support at night time. If this exists, does it need updating to accommodate the specific needs of people with a learning disability and dementia? If you do not have this guidance, or do not work in a residential setting, discuss the points that could be included.

## Key point

Waking at night is often a consequence of dementia. Staff responses and the environment can affect what happens when a person wakes. If a person with dementia wakes during the night and cannot be settled, consider providing them with a drink or snack or engaging them in a quiet activity. One-to-one time overnight can be very productive, reinforcing the importance of waking night staff especially as dementia progresses.

## Further reading

Kerr D & Wilkinson H (2010) *Providing Good Care at Night for Older People: Practical approaches for use in nursing and care homes*. London: Jessica Kingsley Publishers.

Kerr D, Wilkinson H & Cunningham C (2008) *Supporting Older People in Care Homes at Night* [online]. Joseph Rowntree Foundation. Available at: <https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/night-care-older-people.pdf> (accessed September 2018).

# Topic 10: Advanced dementia

Palliative care and end of life are often spoken about together in relation to advanced dementia. However, palliative care can, and often should, begin much earlier in the dementia process. Dementia will ultimately lead to death, usually from an associated condition, such as pneumonia, so it is important to think about what a 'good death' may involve and how a palliative approach can be introduced at an earlier, rather than advanced, stage.

A palliative approach means understanding dying as part of a normal process. It brings together psychological and spiritual aspects of care with social and physical. Key areas include:

- ▶ pain relief
- ▶ making sure that we do not delay or hurry death
- ▶ providing support for the family
- ▶ maintaining a good quality of life.

People with a learning disability generally experience poorer health than people without a learning disability. Additionally, many have more complex needs and a higher degree of unmet medical needs. Yet ironically, people with a learning disability who are dying are less likely to access palliative care services, make use of complementary therapy or attend a hospice, even as a day patient.

## End of life care

Communication difficulties and reduced capacity make decision-making and consent for medical treatment complicated. It is important that the person's wishes around their end-of-life care, location of care and funeral arrangements are known in the early stages of dementia, or preferably even before a diagnosis as part of routine conversations. Indeed, many of these discussions do now take place with people who have a learning disability, just as they do among others without a learning disability. Plans for end of life care and funeral preferences are often routinely discussed as part of advanced care planning or when developing life story work.

Many of us would like to choose where we die and often home is the preferred option. This choice is not always offered to people with a learning disability, because there is a:

- ▶ lack of knowledge about what the person wants, if they are unable to communicate this verbally

- ▶ lack of confidence among staff and carers about what a palliative care approach means
- ▶ need to meet the needs of other residents, if the person lives in shared accommodation
- ▶ lack of knowledge about end-of-life emotional and physical care issues.

People with a learning disability and dementia are often not included in planning for their own end of life because they have not been told they have dementia and they do not know that they are dying, or that they have an illness that will ultimately lead to their death.

## Thinking activity

Consider the stage at which a palliative care approach could be started for a person with a learning disability and dementia and who may be involved.

## Key point

Communication is key; communication with the person with a learning disability, their friends and family, staff and other professionals. It is necessary to think about 'when' a person with a learning disability and dementia will die, rather than 'if'. A palliative care approach should be in place sooner rather than later.

## Further reading

Alzheimer Scotland (2015) *Advanced Dementia Practice Model: understanding and transforming advanced dementia and end of life care*. Edinburgh: Alzheimer Scotland [https://www.alzscot.org/campaigning/advanced\\_dementia\\_model](https://www.alzscot.org/campaigning/advanced_dementia_model) (accessed September 2018).

European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities (2015) *Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe EAPC White Paper* [online]. Available at: <http://www.eapcnet.eu/LinkClick.aspx?fileticket=lym7SMB78cw%3D> (accessed September 2018).

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