

# Learning disabilities and dementia



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A learning disability is a condition that affects the way a person learns new things, understands information, and/or communicates. It could be caused by:

- genetics
- the person's mother having problems in pregnancy or childbirth
- an illness or medical event in childhood or adulthood, such as meningitis or a stroke
- an accident that causes a brain injury

Living with a learning disability and dementia can be physically and emotionally challenging for the person, their family, carers and other people in their support network. However, the right care and support can help everyone manage these challenges as well as possible.

### **Dementia and learning disabilities**

In recent years, the number of people with learning disabilities being diagnosed with dementia has grown. This is partly because people with learning disabilities are more likely to develop dementia, and partly because life expectancy for people with learning disabilities is increasing all the time – and the risk of developing dementia increases with age.

People with a learning disability are also more likely to develop dementia earlier in life. Around one in eight people with a learning disability will develop dementia between the ages of 60 and 65, compared to one in 100 in the general population.

There is a particularly strong link between Down's syndrome and young onset dementia (where symptoms develop before the age of 65), especially Alzheimer's disease:



- One in three people with Down's syndrome will develop dementia in their 50s
- One in 10 will develop it between the ages 40 and 49
- One in 50 will develop it between the ages of 30 and 39

Dementia in people with learning disabilities often progresses, or appears to progress, more rapidly if it is not diagnosed promptly.

### **Recognising the signs of dementia in a person with a learning disability**

Often, memory loss is one of the first and most obvious signs of dementia, but people with a learning disability may show other symptoms first, such as:

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- changes in personality or mood
- poor concentration
- withdrawing from activities they usually enjoy
- difficulty making decisions/making impulsive decisions
- changes in how they live their day-to-day life
- difficulty with tasks and activities they could usually manage independently

Anyone can have a bad day, but if the changes are persistent, getting worse or affecting the person's daily life, you should arrange for them to see their GP. If they do have dementia, getting a diagnosis means support can be put in place as soon as possible.

It is helpful to keep a record to show the GP, including:

- what you noticed
- when it occurred (including the time of day and the situation it occurred in, eg the environment, people they were with, sounds, smells etc)
- whether the change comes and goes, or appears permanent

If the person is under 65, you could also complete the Young Dementia Network's personal checklist as a record of their symptoms – please see Sources of support on p19.

Bear in mind that anyone over the age of 14 who has a learning disability should have an annual health check with their GP – this will help to identify any health problems they are experiencing, including dementia. To ensure the person is offered this check, you can ask the GP to include them on the practice's learning disability register. Please see Sources of support on p18 for more information.

## Getting a diagnosis

The GP should start by assessing whether the person has an underlying treatable condition that could cause similar symptoms to dementia. These include:

- depression
- menopause
- vitamin B12 deficiency
- abnormal thyroid function
- low sodium
- delirium (an acute state of confusion, often resulting from another illness or infection)

To confirm or rule out underlying conditions, the GP may suggest doing blood tests and a urine sample, if the person is willing and able to undergo these tests. If they are unable or unwilling to consent, there may be other ways for the GP to make an assessment, which they should discuss with you and the person themselves. Please see Sources of support on p16 for our leaflet on decision-making for a person with dementia.

The GP may briefly test the person's cognitive abilities and short-term memory by asking them to name some common items, remember a name or address, and draw an everyday object, usually a clock. Some people struggle with these tests because of their learning disability rather than dementia; tell the doctor if this is likely to be the case.

If other conditions are ruled out as possible causes of the changes in the person's memory, behaviour, personality and/or mood, the GP may refer them for further investigation. While dementia

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assessments are typically carried out by a memory clinic, assessing a person with a learning disability can be more difficult and so should involve a multidisciplinary team that includes:

- a psychiatrist
- a community learning disabilities nurse
- a psychologist

To ensure the assessment is accurate and person-centred, do not be afraid to ask for reasonable adjustments to support the person – for example, allowing extra time to answer questions (perhaps by requesting a double appointment), ensuring the environment is calm and quiet to help them focus, and providing information in accessible formats, such as easy-read versions of written resources.

If the person is diagnosed with dementia, the health professional should tell you what type they are thought to have. Different forms of dementia have different symptoms, so having this information can help with planning the person's care and support.

They should also tell you what will happen next in terms of any treatment options, referrals to other specialists, and support services you can access. See Sources of support on p17 for our information on getting the most out of health appointments.

### **Difficulties getting a diagnosis**

Getting an accurate diagnosis of dementia for a person with a learning disability can be difficult. Understanding of learning disabilities and dementia amongst health and social care professionals is variable, and dementia symptoms are often put down to the person's learning disability or 'behaviours'. In some cases, specialist dementia services like memory clinics do not even accept referrals for people with learning disabilities.





As a result, many people living with a learning disability and their families lack support, understanding and guidance in getting a diagnosis of dementia. This places extra pressure on the person, who may be stressed and confused about the changes in themselves and the appointments and tests they are going through, and on the people who care for them.

If you need support with learning disabilities and dementia, including advice on getting a diagnosis and what to do if the person is reluctant to see their GP or have tests, please call our free Helpline to speak to a specialist dementia nurse – see Sources of support on p16.



### Lasting power of attorney

If the person you care for has not completed a lasting power of attorney (LPA), it is important to apply as soon as possible. It will allow you and/or other nominated people to make decisions about their health and welfare and/or property and financial affairs if they lose the capacity to do so themselves.

The equivalent of an LPA in Scotland is called power of attorney; and in Northern Ireland, enduring power of attorney.

If the person already lacks capacity and has not made an LPA, a health or care professional may need to carry out a mental capacity assessment and then work with you, the person and other people



who are involved in their care to make decisions on their behalf, in their best interests.

Alternatively, you can apply to the Court of Protection to become the person's 'deputy' and make a decision for them; however, it is always best to make a lasting power of attorney. Please see Sources of support on p17-19.

### **Living with a learning disability and dementia**

If a person with a learning disability is diagnosed with dementia, their care and support needs will need to be reassessed. In addition to seeing their usual health and social care team, the person may be referred to other professionals like a social worker, occupational therapist or psychiatrist. Where possible, keep the person informed about any changes to their care team.

To establish what care and support the person needs, including home adaptations, assistive living equipment and paid care, and whether you can access funding for these, you can request a needs assessment by contacting Social Services. You can also request a carer's assessment for yourself, which will identify what support would help you in your caring role.

You can speak to your GP, social worker or local council or look online for information on support groups and services in your area, such as dementia specialist Admiral Nurse services or MacIntyre Memory Cafés for people with learning disabilities and dementia. Please see Sources of support on p16 and 18 for more information.

The following tips may help to make life easier for the person with the learning disability and their carers:

### **Healthy living advice**

- Ensure the person is eating and drinking well. Look for signs of

hunger or thirst that they might not be able to express, such as weight gain/loss, constipation and dehydration. See Sources of support on p17 for more information on eating and drinking for people with dementia

- Encourage the person to make healthy lifestyle choices, like stopping smoking and reducing/cutting out alcohol
- Support them in getting enough sleep, as tiredness can make dementia symptoms worse. See Sources of support on p17 for information on good sleep habits
- Encourage the person to take part in physical activity to boost their health and wellbeing and help them reach or maintain a healthy weight – ask them what sort of activities they enjoy to make exercise meaningful and enjoyable
- Ensure they attend their health appointments, including check-ups with their GP/specialist, optician, dentist and audiologist (hearing specialist). Things like infections, pain, sight and hearing problems can all make their dementia seem worse

### **The living environment**

Whether the person with a learning disability and dementia lives independently, with family or in supported accommodation, take a look at their environment to identify ways to keep them safe and help them maintain their independence – for example, removing rugs that could be tripped over, labelling cupboards with what is inside, and fitting safety devices to stop cookers and taps being left on.

Please see Sources of support on p17 for information on assistive technology, living aids and making the home safe and comfortable for a person with dementia.

Give the person more time for daily tasks – these tasks may take



longer if they feel rushed or under pressure. Allow them to maintain as much independence and control of their day-to-day life as possible, with support if necessary.

If the person lives in shared accommodation for people with learning disabilities, take the time to explain to other residents why these changes are happening. This will help them feel included and gain understanding of how the person's dementia affects them.

Staff may wish to access additional dementia training to help them increase their own knowledge, communicate effectively with the person with the diagnosis, and help other residents understand what is happening.

If the person lives with family, it is important to consider how their care may need to be adapted as their dementia progresses. For example, if they live with elderly parents who are frail or have health and mobility conditions of their own, a paid home carer could relieve some of the physical and emotional strain.

If the person eventually needs additional support from a home carer or to move into a care home, staff will need specialist knowledge and skills to support their needs. Some care homes will accept a person with a mild to moderate learning disability, but a specialist home may be more suitable for a person with complex needs. Again, aim to include the person in these decisions as far as possible.

### Communication

Many people with learning disabilities and dementia can have difficulties with communicating, understanding, and/or processing and remembering information, so be prepared to change how you communicate. For example:

- Try to keep explanations clear and sentences short
- If you are giving the person instructions, break them down into individual steps
- Keep questions simple and direct, rather than open-ended – eg “Shall we go shopping today?” instead of, “Where shall we go today?”

Always be guided by your knowledge of the person – everyone with a learning disability and dementia is unique, so tailor your support so that it is meaningful and makes sense to them.

It is a good idea to help the person create a life story – a record of who they are, important details about their life, their family and friends, their values, and what matters to them, such as their gifts,

talents and things they are proud of. This can help other people, including carers, understand more about them and communicate better with them. Please see Sources of support on p17 for more information.

If the person lives in supported accommodation or a group setting, staff and other residents will need to be aware of their dementia diagnosis and how it may affect their personality, behaviour and ability to communicate. Easy-to-read leaflets are available from MacIntyre's website at [macintyrecharity.org](https://www.macintyrecharity.org)

Those who support the person could also consider enrolling in carer education programmes that are available from organisations like Dementia Carers Count and tide: please see Sources of support on p19.

### Emotional wellbeing

It is often assumed that people with dementia or learning disabilities cannot experience anxiety and depression, but this is not the case. However, they may have difficulty communicating their feelings, so it is important to be aware of their emotions. See Sources of support on p16 for our information on anxiety and depression in people with dementia.

As far as possible, help the person keep to their usual routine, with adaptations and support if necessary – making big or sudden changes can be confusing and distressing. Encourage the person to continue with activities they enjoy, including socialising, with adjustments or allowances if these become more difficult.

Look for opportunities to create laughter and joy, and spend time together doing meaningful activities you both enjoy to maintain a connection between you. The person might not remember these moments, but they may remember how they made them feel.



### Advance care planning

It is important to work with the person and their care team to create an advance care plan that sets out their wishes for their future health and social care, such as where they would like to be cared for and medical treatments they do/do not want to receive. This is not legally binding but will help guide their care. Please see Sources of support on p16.

Where possible, the person with a learning disability should be involved in all aspects of creating the plan. You might find it helpful to use tools such as Talking Mats (a communication system based on pictures and symbols) to help them convey their wishes – please see Sources of support on p19.

Creating an advance care plan with the person's involvement will take time, so aim to start the process as soon as possible. Try to review it on a regular basis – especially if you notice changes in the person's symptoms and behaviours – to ensure it adapts to reflect their wishes and preferences.

To ensure you get the help you need as a carer, you can request a carer's assessment from Social Services to determine what support and resources you would benefit from, and whether you are eligible for funding. Please see Sources of support on p16.

You can also ask your GP surgery to register you as a carer so you receive support such as carer health checks, free flu jabs, flexibility with doctor's appointments and prescription services. This will also help with applications for benefits such as Carer's Allowance and Blue Badge parking. Please see Sources of support on p16 and p18.



## Sources of support

To speak to a dementia specialist Admiral Nurse about learning disabilities and dementia, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can pre-book a phone or video call appointment with an Admiral Nurse: visit [▶ dementiauk.org/book](https://dementiauk.org/book)

### Dementia UK resources

#### Advance care planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

#### Anxiety and depression in a person with dementia

[▶ dementiauk.org/managing-anxiety-and-depression](https://dementiauk.org/managing-anxiety-and-depression)

#### Blue Badge parking

[▶ dementiauk.org/blue-badge-parking](https://dementiauk.org/blue-badge-parking)

#### Capacity and decision-making

[▶ dementiauk.org/capacity-decision-making](https://dementiauk.org/capacity-decision-making)

#### The carer's assessment

[▶ dementiauk.org/the-carers-assessment](https://dementiauk.org/the-carers-assessment)

#### Communication tips

[▶ dementiauk.org/better-communication](https://dementiauk.org/better-communication)

#### Delirium

[▶ dementiauk.org/delirium](https://dementiauk.org/delirium)

### **Dementia and sleep**

- [dementiauk.org/good-habits-for-bedtime](https://dementiauk.org/good-habits-for-bedtime)

### **Eating and drinking**

- [dementiauk.org/eating-and-drinking](https://dementiauk.org/eating-and-drinking)

### **Financial and legal sources of support**

- [dementiauk.org/financial-and-legal-sources-of-support](https://dementiauk.org/financial-and-legal-sources-of-support)

### **Getting a diagnosis of dementia**

- [dementiauk.org/getting-a-diagnosis-of-dementia](https://dementiauk.org/getting-a-diagnosis-of-dementia)

### **Getting the best out of GP and other health appointments**

- [dementiauk.org/getting-the-best-out-of-gp-and-other-health-appointments](https://dementiauk.org/getting-the-best-out-of-gp-and-other-health-appointments)

### **Good hydration for a person with dementia**

- [dementiauk.org/hydration](https://dementiauk.org/hydration)

### **Lasting power of attorney (England and Wales)**

- [dementiauk.org/lasting-power](https://dementiauk.org/lasting-power)

### **Living aids and assistive technology**

- [dementiauk.org/living-aids-and-assistive-technology](https://dementiauk.org/living-aids-and-assistive-technology)

### **Life story work**

- [dementiauk.org/life-story](https://dementiauk.org/life-story)

### **Making the home safe and comfortable for a person with dementia**

- [dementiauk.org/safe-comfortable-home](https://dementiauk.org/safe-comfortable-home)

### **The importance of registering as a carer with your GP**

- [dementiauk.org/the-importance-of-registering-as-a-carer-with-your-gp](https://dementiauk.org/the-importance-of-registering-as-a-carer-with-your-gp)

### **Young onset dementia: getting a diagnosis**

➤ [dementiauk.org/young-onset-dementia-getting-a-diagnosis](https://dementiauk.org/young-onset-dementia-getting-a-diagnosis)

### **Understanding young onset dementia**

➤ [dementiauk.org/what-is-young-onset-dementia](https://dementiauk.org/what-is-young-onset-dementia)

### **MacIntyre resources**

Website: ➤ [macintyrecharity.org](https://macintyrecharity.org)

General enquiries: 01908 230100

Email: ➤ [hello@macintyrecharity.org](mailto:hello@macintyrecharity.org)

### **Dementia and learning disability resources**

➤ [macintyrecharity.org/our-approach/dementia](https://macintyrecharity.org/our-approach/dementia)

### **Macintyre Memory Cafés**

➤ [macintyrecharity.org/our-approach/health/dementia/memory-cafes](https://macintyrecharity.org/our-approach/health/dementia/memory-cafes)

### **Other sources of information**

#### **Annual health checks for people with learning disabilities**

➤ [nhs.uk/conditions/learning-disabilities/annual-health-checks](https://nhs.uk/conditions/learning-disabilities/annual-health-checks)

#### **Apply for a needs assessment by Social Services**

➤ [gov.uk/apply-needs-assessment-social-services](https://gov.uk/apply-needs-assessment-social-services)

#### **BILD: growing older with learning disabilities**

➤ [bild.org.uk/growing-older-with-learning-disabilities-gold](https://bild.org.uk/growing-older-with-learning-disabilities-gold)

#### **Carer's Allowance**

➤ [gov.uk/carers-allowance](https://gov.uk/carers-allowance)



### **Dementia Carers Count**

➤ [dementiacarers.org.uk](https://dementiacarers.org.uk)

### **Deputies: becoming a deputy for someone who lacks capacity**

➤ [gov.uk/become-deputy](https://gov.uk/become-deputy)

### **Down's Syndrome Association**

➤ [downs-syndrome.org.uk](https://downs-syndrome.org.uk)

### **Enduring power of attorney (Northern Ireland)**

➤ [nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney](https://nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney)

### **Foundation for People with Learning Disabilities**

➤ [learningdisabilities.org.uk](https://learningdisabilities.org.uk)

### **National Autistic Society**

➤ [autism.org.uk](https://autism.org.uk)

### **Power of attorney (Scotland)**

➤ [mygov.scot/power-of-attorney](https://mygov.scot/power-of-attorney)

### **Scope: the disability equality charity**

➤ [scope.org.uk](https://scope.org.uk)

### **Talking Mats**

➤ [talkingmats.com](https://talkingmats.com)

### **tide: together in dementia everyday**

➤ [tide.uk.net](https://tide.uk.net)

### **Young Dementia Network personal checklist**

➤ [youngdementianetwork.org/personal-checklist](https://youngdementianetwork.org/personal-checklist)

**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:  
**0800 888 6678** or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:  
[👉 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit [👉 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

**Thank you.**



**DementiaUK**  
Helping families face dementia



**dementiauk.org • info@dementiauk.org**

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