



MacIntyre

Providing support...your way



DementiaUK

Helping families face dementia

Learning disabilities and dementia



A learning disability is a condition that affects the way a person:

- learns new things
- understands information
- communicates

A learning disability can 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 or dementia can be physically and emotionally challenging – for you and the person you care for. These challenges are often greater if the person has both a learning disability **and** dementia.

However, the right care and support can help you both find the strength to cope with the bad days, and the energy to enjoy the good days.

Dementia and learning disabilities – an overview

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.

Around one in 10 people with a learning disability will develop young onset dementia (when symptoms develop at or before the age of 65).

There is a particularly strong link between Down's syndrome and dementia:

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

Dementia in people with learning disabilities often progresses – or

appears to progress – more rapidly if a timely diagnosis isn't made.

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

Often, memory loss is one of the first and most recognisable signs of dementia, but this may not be the case for people with a learning disability. They might demonstrate other symptoms first, such as:

- changes in their personality or mood
- difficulty making decisions
- changes in the way they live their day-to-day life

- difficulty with things they could normally manage independently

Everyone can have a bad day, but if the person seems to be having a lot of bad days or the characteristics of their learning disability seem to be getting worse, there may be cause for concern.

If you're noticing changes, it is helpful to keep a record of:

- what you noticed
- when it occurred
- whether the change comes and goes, or appears permanent



In this photo: Rachel

If the changes you notice are persistent, getting worse or having an impact on the person's activities or daily living, you should arrange for them to see their GP, taking your record with you.

A number of other conditions and illnesses can cause changes similar to dementia, so it's important that these are ruled out by the GP.

If it does turn out that the person has dementia, an early diagnosis means support can be put in place as soon as possible to help them live better with the condition.

Getting a diagnosis

The GP should start by assessing whether the person has an underlying treatable condition, for example depression, vitamin B12 deficiency, or abnormal thyroid function. They should also consider whether the hormonal changes caused by the menopause may be responsible.

To rule out health conditions like these, the GP should offer to take blood tests, a chest X-ray (if necessary), a brain scan and a urine sample, if the person is willing and able to undergo such tests.

The GP may also briefly test the person's cognitive abilities by asking them to:

- state what day and date it is
- name some common items
- remember something simple to test concentration and short-term memory, eg an address

It's important to bear in mind that the person may struggle with these tests because of their learning disability, rather than dementia, for example if they have difficulty communicating. You should tell the doctor if this is the case.

If other physical or mental health conditions have been ruled out as possible causes of the changes in the person's memory, behaviour, personality and/or mood, the GP may then refer them for further investigations.

These could be:

- at a memory clinic – a specialist clinic for dementia diagnosis, treatment and support
- at a learning disability clinic
- with a doctor who specialises in learning disability and/or dementia, eg a psychiatrist

If dementia is diagnosed, the health professional should tell you what type of dementia the person is believed to have. Different types of dementia have different symptoms and knowing 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 that might be suitable, other specialists that the person might be referred to, and support that you and the person you care for can access.

See Sources of support on p10 for details of 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 still patchy, which means that dementia symptoms are often put down to the person's learning disability or 'behaviours'.

In some cases, specialist dementia services like memory clinics don't even accept referrals for people with learning disabilities.

As a result, many people living with a learning disability and

their families experience a lack of support, understanding and guidance in getting a diagnosis of dementia. This places extra pressure on the person with a learning disability, who may be stressed and confused about the changes in themselves, and on the people who care for them.

If you need support with learning disabilities and dementia, including advice on getting a diagnosis, please call our free Helpline to speak to a specialist dementia nurse – see Sources of support on p10 for contact details and our information leaflet on getting a dementia diagnosis.

Living with a learning disability and dementia

Once a person with a learning disability has been diagnosed with dementia, their care and support needs should be reassessed in light of their diagnosis.

In addition to seeing their usual health and social care team, they may be referred to a social worker, occupational therapist, psychiatrist and/or other health and social care professionals.

You can also speak to your 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.

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

Healthy living advice

- Ensure the person is eating and drinking well – never assume they are. 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 p10 for more information on eating and drinking and on good hydration for a person with dementia

- Encourage them 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 p10 for information on good sleep habits
- Encourage the person to take part in physical activity to boost their wellbeing, improve their overall health and help them remain mobile
- Keep up with their health appointments, including check-ups with their GP/specialist, optician, dentist and audiologist (hearing specialist). Things like infections, pain, hearing problems and sight loss can all make their dementia seem worse

Everyday living advice

- Make the person’s home dementia-friendly – for example, by removing trip hazards, labelling cupboards with what’s inside, and fitting safety devices to stop cookers and taps being left on. This will help the person live as safely and independently as possible. See Sources of support on p10 for information on making the home safe and comfortable for a person with dementia
- Request a Needs Assessment from Social Services to establish what care and support the person may need in their daily life and whether you can access funding – you can apply at [gov.uk/apply-needs-assessment-social-services](https://www.gov.uk/apply-needs-assessment-social-services)
- Give the person more time for daily tasks – feeling rushed may make them feel stressed, and tasks may take longer if they’re under pressure
- Allow the person to maintain as much independence as is safe and appropriate, with support, and make every effort to ensure



In this photo: Mark

that they remain in control of their day-to-day life

Feelings and emotions

- Be aware of the person’s feelings and emotions. It is often assumed that people with dementia or learning disabilities cannot experience anxiety and depression, but this is not the case – they may just not be able to communicate how they are feeling. See Sources of support on p10 for our information on anxiety and depression in people with dementia
- As far as possible, the person should remain in their usual routine, with adaptations and support if necessary

- making big or sudden changes can be unsettling, confusing and distressing
- Encourage the person to continue with the things they still enjoy, but be prepared to make adjustments or allowances for the things they can no longer do
- Look for opportunities to create laughter and joy. The person might not remember what you said, but they are likely to remember how you made them feel
- Spend time together doing activities you both enjoy to maintain a connection between you

Communication tips

- Many people with learning disabilities and dementia have difficulties communicating, understanding what's been said, or processing and remembering information
- Be prepared to change some methods of communication – see Sources of support on p10 for our information on communication tips
- Try to keep explanations simple and sentences short
- When you ask the person questions, try to keep them simple and direct, rather than open-ended – eg “Shall we go shopping today?”, instead of, “Where shall we go today?”
- Help them create a ‘Life Story’ – a record of who they are, important details about their life, their family and friends, their values and things that matter to them. This can help other people, including carers, understand more about them and communicate better with them
- Help the person’s family and friends to understand the changes that are happening. Easy-to-read leaflets are available from MacIntyre’s website: macintyrecharity.org
- Consider taking part in some of the carer education programmes that are available from organisations like Dementia Carers Count and tide (see Sources of support on p11)

Planning for the future

- If the person you care for has not completed a lasting power of attorney (LPA), it's important to apply as soon as possible. It will allow you and/or other nominated people to make decisions about health and welfare and/or property and financial affairs if, in the future, the person loses the capacity to do so themselves
- Work with the person to complete an Advance Care Plan – a document that sets out their

wishes for future medical and social care

- Request a Carer's Assessment – this is carried out by your local authority to determine what support and resources will help you as a carer, and whether you're eligible for funding
- Ask your GP surgery to register you as a carer so you receive support such as carer health checks and a free flu jab

See Sources of support (below and overleaf) for more information on all of these.



In this photo: Diane

Sources of support

If you would like to speak to a dementia specialist Admiral Nurse about learning disabilities and dementia or any other aspect of dementia, please call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

If you would prefer to pre-book a phone or video call with an Admiral Nurse, please visit dementiauk.org/get-support/closer-to-home

Dementia UK leaflets and resources:

Getting the best out of GP and other health appointments
dementiauk.org/the-best-from-gp-appointments

Getting a diagnosis of dementia
dementiauk.org/getting-a-diagnosis-of-dementia

Making the home safe and comfortable for a person with dementia
dementiauk.org/safe-comfortable-home

The Carer's Assessment
dementiauk.org/the-carers-assessment

Advance Care Planning
dementiauk.org/advance-care-planning

Tips for communication
dementiauk.org/better-communication

Dementia and sleep
dementiauk.org/good-habits-for-bedtime

Life Story work
dementiauk.org/life-story

Anxiety and depression in a person with dementia
dementiauk.org/managing-anxiety-and-depression-in-a-person-living-with-dementia

Eating and drinking
dementiauk.org/eating-and-drinking

Good hydration for a person with dementia
dementiauk.org/hydration

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Capacity and decision-making
dementiauk.org/capacity-decision-making

MacIntyre resources:
Website: macintyrecharity.org

General enquiries:
01908 230100

Email:
hello@macintyrecharity.org

Dementia and learning disability resources
macintyrecharity.org/our-approach/dementia

Macintyre Memory Cafés
macintyrecharity.org/our-approach/dementia/memory-cafes

Other sources of information:

BILD: growing older with learning disabilities
bild.org.uk/growing-older-with-learning-disabilities-gold

Foundation for People with Learning Disabilities
learningdisabilities.org.uk

Hidden in plain sight – dementia and learning disability booklet
learningdisabilities.org.uk/learning-disabilities/publications/hidden-plain-sight-dementia-and-learning-disability

Dementia Carers Count
dementiacarers.org.uk

tide: together in dementia everyday
tide.uk.net

Down's Syndrome Association
downs-syndrome.org.uk

National Autistic Society
autism.org.uk

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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