Dementia is a condition that anyone can develop. As we get older, the risk of getting dementia increases for everyone. People who have a learning disability, especially Down’s syndrome, are more likely to develop dementia at a younger age. This factsheet is written for carers. It explores and explains some of the specific issues and options for people who have both a learning disability and dementia.

If you already care for a person who has a learning disability, you will know them, and how to support them, best. When someone is diagnosed with dementia, they may have new needs that have to be met. Every person with dementia is affected in different ways – for example, some people will have memory problems, and others will find it difficult to do things they’ve always been able to do.

It is important to recognise that people can and do live well with dementia. Alzheimer’s Society provides information, advice and support for people who have a learning disability and dementia, and for carers.

If you would like more detailed information on dementia, read our booklet 872, The dementia guide, and our factsheet 400, What is dementia? Factsheet 400 is also available in Easy Read format which is written for people who have learning disabilities – factsheet ER1, What is dementia?

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What is dementia?

Dementia is not a normal part of ageing. It occurs when the brain is damaged by disease, such as Alzheimer’s disease, or a series of strokes. Symptoms may include memory loss and difficulty with thinking, problem-solving and communicating. A person’s mood and behaviour can also change.

There are many diseases that cause dementia. The most common types of dementia are Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. If you would like more detailed information on dementia, see factsheet 400, What is dementia? or booklet 872, The dementia guide.

Dementia will get worse over time, and there is no cure. This can be hard to accept, but there are a range of things that can support people to live well with the condition. There are also treatments that can help. See the section ‘Treatment and support’ later in this factsheet.

People who have a learning disability are now living longer, thanks to better medicine, care and opportunities to be supported in the community. This means that, if the person you care for has a learning disability, they are more likely to live to an age where they may develop dementia.

People who have learning disabilities are at an increased risk of getting dementia. If they have Down’s syndrome, they have an even higher risk. There is more specific information in the ‘Down's syndrome and dementia: assessment and diagnosis’ section later in this factsheet.

How does dementia affect people who have learning disabilities?

Dementia affects people who have learning disabilities in similar ways to people who don’t have learning disabilities. But there are some differences.

If a person has a learning disability, they:

- are more likely to get dementia as they get older than people who do not have a learning disability
- are more likely to get dementia at a younger age, particularly if they have Down’s syndrome
- often show early symptoms of dementia that are different to those in people without learning disabilities
- are more likely to have other health conditions that aren’t well managed – these can affect how well they live with dementia
- may find it more difficult to get an early diagnosis from the doctor – this is because of difficulties they already experience as a result of their learning disability
- may find that dementia gets worse more quickly
- may already communicate differently to other people
- may already have social care at home, or have help to live on their own
- might need help from experts who know about dementia, to help them understand the changes that are happening and to live well as their dementia gets worse.
Dementia and Down’s syndrome

Scientists are not sure why some people who have Down’s syndrome develop dementia and others don’t. The reasons why people with Down’s syndrome are at a higher risk of Alzheimer’s disease in particular are also not well understood. It is thought to be due to chromosome 21. Most people with Down’s syndrome have an extra copy of chromosome 21. This leads to an build-up of a protein (amyloid precursor protein) which forms plaques on the brain. These plaques are a feature of Alzheimer’s disease.

When people who have Down’s syndrome develop dementia it is usually, but not always, because of Alzheimer’s disease. By the age of about 40, almost all people with Down’s syndrome have changes in the frontal lobe of their brain. However, not all people who have Down’s syndrome will develop the symptoms of dementia.

1 in 3 people who have Down’s syndrome develop dementia in their 50s. This increases to nearer 2 in 3 people with Down’s syndrome who are over the age of 60.

Symptoms of dementia in people who have learning disabilities

For people who have a learning disability, the signs of dementia can vary. The early signs of dementia can be different to those in people who do not have a learning disability. These include changes in personality, or behaviour which leads to a change in daily living skills. These symptoms can make diagnosing dementia harder. They are not what people typically think of as dementia, and are often associated with other conditions. If the person has a complex or profound learning disability, the early signs of dementia may not be obvious. This can also make it harder to diagnose, and any diagnosis is likely to take longer than in a person who doesn’t have a learning disability.

Dementia is progressive, which means the symptoms gradually get worse over time. How quickly this happens varies greatly from person to person. As dementia progresses, the person who has a learning disability may act in ways that seem out of character. These changes can be distressing for you and others close to the person. This may include the person asking the same question over and over, pacing, and becoming restless or agitated. In the later stages of dementia, the person may have physical symptoms such as muscle weakness or weight loss, or changes in their sleep pattern and appetite.

Down’s syndrome

The symptoms of dementia in people who have Down’s syndrome are similar to those in people who do not have Down’s syndrome. But there are some differences. The person’s behaviour and personality may change and they might be more stubborn, irritable or withdrawn. They may also struggle with day-to-day activities they previously managed to do. People who have Down’s syndrome may also lose basic skills such as walking, continence and swallowing earlier than people who don’t have a learning disability.

The most common sign of dementia in older people is memory loss, but this is a less common sign of dementia in a person who have Down’s syndrome. This might be because they already have poor short-term memory.

Many people who have Down’s syndrome live with epilepsy or fits. If in later life they start to have fits, it is almost always a sign of dementia, so it’s very important that this is investigated. If they have serious fits or seizures, it’s likely their health will get worse more quickly. Over 80% of people who have Down’s syndrome and dementia develop seizures.

If the person you care for has Down’s syndrome, they are more likely to have hearing loss, depression, seizures and an underactive thyroid, and these may be made more complicated by their dementia. If you have any concerns or worries, speak to their GP or community learning disability nurse.
Other learning disabilities

Dementia in people who have a learning disability other than Down’s syndrome is less well studied and symptoms can vary a lot. If the person’s learning disability is mild, you will probably find that the dementia appears and gets worse in the same way as people who don’t have a learning disability.

Cognitive symptoms may include problems with thinking or memory such as:

- day-to-day memory – for example, difficulty recalling events that happened recently
- concentrating, planning or organising – for example, difficulty making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal)
- language – for example, difficulty following a conversation or finding the right word for something
- visuospatial skills – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions
- orientation – for example, losing track of the day or date, or becoming confused about where they are.

You may also find that the person’s mood becomes changeable. They may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).

For people with more complex or profound learning disabilities, the initial symptoms are less typical. The early symptoms may involve changes in personality and behaviour. This can make diagnosing dementia more difficult.

Identifying dementia in someone who has a learning disability

You know the person you care for, best. Dementia may change the way they do things or how well they do things. You might notice that their thinking, reasoning or language is affected. If you notice this is ongoing rather than a one-off occurrence it should be investigated, although it it doesn’t necessarily mean that the person you care for has dementia.

Any changes that you or the person’s other carers, friends or family notice, can play an important part in helping to spot early signs of dementia. For example, the person not being able to do the things they could before, or changes in their behaviour. If you are concerned, you should tell the person’s GP or learning disability team as soon as possible. If the person is experiencing symptoms, they can have an assessment that aims to diagnose dementia in people who have a learning disability. This is different to the assessment for identifying dementia in people who do not have a learning disability.

The next section focuses on Down’s syndrome – it includes specific tests that are relevant for people with Down’s syndrome.

About 1 in 5 people with a learning disability (other than Down’s syndrome) who are over the age of 65 will develop dementia.
Down’s syndrome and dementia: assessment and diagnosis

Assessment

Everyone who has Down’s syndrome should have a baseline test (or assessment) that works out the person’s current level of functioning (looking at their skills, abilities and personality) by the age of 30. This makes it easier to see changes and spot possible health changes in the future, including dementia.

An adult who has Down’s syndrome should be offered a health check once a year with their GP to check:

- their physical health (weight, heart rate and blood pressure, as well as blood and urine tests)
- their vision and hearing
- their medicines
- how they communicate
- their lifestyle and mental health (including checking for depression)
- for any changes that may suggest they have dementia.

Their GP might recommend that they see a specialist. As part of the health check, the person who has Down’s syndrome should have an agreed health action plan. This gives you advice on how you can help them to stay healthy.

The assessment for dementia is best done by a team of different people (called a multidisciplinary team). They should all be specialists in learning disabilities, apart from the GP, who may not be a specialist. This team is likely to include:

- a psychiatrist
- a community learning disability nurse
- an occupational therapist
- a clinical psychologist.

The assessment will include the following stages.

A detailed look at personal history

A personal history should include any important changes in the person’s life, such as moving home, a favourite care worker leaving or a recent death of someone close to them. The team should speak to the person (where possible), the main carer and any care service staff who know the person well and understand them. This is to find out how the person who has Down’s syndrome feels about things and how they communicate.

A full health assessment

A full health assessment should rule out any physical problems that could cause changes in behaviour. There are lots of conditions that have the same signs as dementia but are treatable (for example an underactive thyroid, which is more common in people who have Down’s syndrome). Any medicine that the person is taking will be reviewed, and their vision and hearing should be tested too, because problems with these are more common in people who have learning disabilities.

Cognitive and mental state assessments

The person will be asked to complete some tests to help work out if they have dementia or if there are other conditions (such as depression) that may be causing the problems they are having. The team will aim to observe the person including their alertness, their mood and their orientation to time, place and person. There are a range of different assessments that have been developed to help identify dementia in people with Down’s syndrome and other learning disabilities.

The assessment should involve the person who has a learning disability wherever possible. If this is not possible, the team may ask the carer to complete an assessment about the difficulties the person is having. The team may also ask the person and their carer to complete assessments that look at the person’s mental health and their ability to do day-to-day activities. These will then be reviewed and used to help inform any diagnosis. The same assessments should be used each time the person is assessed. These can then be compared and the team can see how the person’s functioning has changed over time.
Environmental assessment

This will look at how well the person’s home environment suits them. It will look at:

- how appropriate it is, based on the person’s changing needs
- the level and quality of support available (including during the night)
- whether the person has appropriate and meaningful, individualised daytime activities.

Special investigations

Special investigations are used to try to rule out other health conditions (such as a brain tumour or a brain bleed), or when doctors are unsure whether the person has dementia. The person you care for may be sent for a brain scan. These can be distressing and the results may be difficult to interpret. Even with a thorough assessment, it will not always be possible to make a clear diagnosis of dementia in the person who has Down's syndrome. It may be necessary to wait and monitor how the person gets on. Repeating the assessment several months later is the next step.

Receiving a diagnosis of dementia

When you find out that the person you care for has dementia it can make you and those close to them feel worried, upset, angry and sad. The person you are caring for may also feel this range of emotions. Some people also feel relieved, as they have an explanation for why there have been changes in the person’s health and wellbeing or why they’re finding things difficult. As a carer it is important that you receive support too. See our factsheets 524, Understanding and supporting a person with dementia and 523, Carers: Looking after yourself for more information.

Sharing the diagnosis

People who have learning disabilities have a right to know about their diagnosis. However, the person may not fully understand what dementia is, or what it will mean for them. If you are explaining it to them you should try to make it as easy as possible for them to understand. Using familiar language that they use every day will help.

‘Jenny’s diary’ is a research-based booklet that has been developed to help people who have learning disabilities understand dementia. It is freely available to download at www.learningdisabilityanddementia.org/jennys-diary

As a carer, you might want to read our factsheet 400, What is dementia? You might find it helpful to read our Easy Read factsheet ER1, What is dementia? with the person while you are explaining their diagnosis. The Easy Read factsheet has been specifically designed for people who have learning disabilities.

The person may be living with a partner, friend or other residents who have learning disabilities when they are diagnosed. Again, sharing Easy Read information may help those around the person to understand what is happening. It’s important for you to ask the person you are caring for whether they are happy for you to share this information. If the person doesn’t have capacity to make this decision then it should be made in their best interests.

You may also want to read our Easy Read factsheet ER2, Supporting a person with dementia with the person you are caring for, as this might help them to understand what their diagnosis means, and to better manage their feelings.

It’s best to share a diagnosis with someone in a way that is sensitive to how well they can understand the information you are giving them. Depending on their abilities, it might be best to share information about their diagnosis in small steps. This means:

- thinking about what the person currently understands about their past, present and future – for example, if they have an understanding of what their future may look like, they may understand more about how dementia might affect them
- deciding which small pieces of information are needed at the time, and the best way to give it
- giving one piece of information at a time
- checking they understand regularly – this will change over time.
There are other things that may help when it comes to talking about dementia. These may also be appropriate for other people with learning disabilities, who may live with the person:

- Use language that the person uses and is familiar to them.
- Use pictures if this helps them to understand.
- Everyone who talks to the person should use the same words.

If the person lives in shared accommodation, it can be helpful to explain what is happening to the other people they live with. This should include explaining they can still be friends with the person and that there are things they can do to help, for example supporting the person with hobbies.

### Care plan

After the person who has a learning disability receives a diagnosis of dementia, receiving the diagnosis, the person’s care or multidisciplinary team will agree a care plan. This is agreed with the person and those supporting them, to help them to live well with dementia. The team will talk about this plan with the person with a learning disability and dementia, you and any other people who support and care for them. This team will agree when the plan will be updated, including checking for and looking into any changes in the person’s health, behaviour or living skills.

With the right support in place, many people with dementia are able to carry on doing things for themselves that they enjoy.

### Planning for the future

Thinking and talking about the future of the person you care for, and particularly their care at the end of life, can be very difficult to do. When you find that you can both think ahead, it’s good to try to support the person in planning for how they would like to be cared for as their dementia progresses. The best time for them to make or change any plans about what they would like for their future is soon after a diagnosis.

You may already have had discussions around the person’s choices while helping them to do life story work. They may also have already thought about and put plans in place for the future, such as a Lasting power of attorney (LPA) (or an Enduring power of attorney in Northern Ireland). In England and Wales it’s possible to make an LPA to cover health and care issues as well as financial ones. In Northern Ireland it is currently only possible to have an Enduring power of attorney for financial matters.

If the person doesn’t have the ability to make decisions about these things (known as having the ‘mental capacity’) and hasn’t set up an LPA, you can apply to become a deputy (in England and Wales). Deputyship is a way to get the legal authority to make decisions on someone’s behalf, if that person no longer has the ability to make an LPA. For more information see factsheet 530, Deputyship.

If you are in Northern Ireland it may be necessary to appoint a controller. For more information see factsheet NI472, Enduring power of attorney and controllership.

By law, the person with dementia should be as involved in advance care planning as much as they are able. A person’s ability to make decisions about things (their mental capacity) depends on the situation, so even if they do not have capacity to make some decisions, they may have capacity to make others. If decisions are being made for the person it’s important they are made in the person’s best interests and that they are the least restrictive option. For more information see factsheet 460, Mental Capacity Act 2005.

You might also want to read our booklet 15 10, Planning ahead and factsheet 472, Lasting power of attorney. For information about advance statements and advance decisions in England and Wales see our factsheet 463, Advance decisions and advance statements, and for laws that relate to Northern Ireland see factsheet NI467, Financial and legal tips.

You can also find more information on making decisions about the future in booklet 872, The dementia guide.
Treatment and support

A person with a learning disability can live well with dementia if they have a range of treatment, support and activities. Part of this support is seeing a psychiatrist who specialises in learning disabilities, as well as staff from the learning disability services. Treatments can include drugs and non-drug approaches.

Medicines

At the moment, there is no cure for dementia. There are some medicines that are used to try to make the symptoms of Alzheimer’s disease better, and these work for some people until their condition gets too advanced. See factsheet 407, Drug treatments for Alzheimer’s disease.

Donepezil (also known as Aricept) is one of the drugs that is sometimes given to people who have Alzheimer’s disease. People with Down’s syndrome and Alzheimer’s disease may be prescribed anti-dementia medication. Although there is no conclusive evidence that these drugs are effective, anecdotal evidence suggests they may improve the quality of life for the person and those supporting them.

Drugs like donepezil can cause side effects. If the person has health conditions such as heart or stomach problems, this medicine may not be offered.

Another drug used to treat Alzheimer’s disease is called memantine and the doctor might suggest this. However, the evidence suggests it doesn’t work for people with dementia and Down’s syndrome.

Changes in behaviour

If the person you care for already behaves in ways that are distressing (for example, becoming agitated or aggressive) this can get worse if they have dementia. It may also affect what they sense is real and what isn’t. Understanding this can help you to understand what the person is feeling, and to interpret their behaviour. It’s important to look at what may be causing the changes in their behaviour, so that you can try to put strategies in place to help.

Involving others who help with the person’s care and support is an important part of finding ways to manage or prevent this behaviour. It’s really important for people with learning disabilities and dementia to have consistency. This should include consistency with carers, their routine and where they live.

Working together will make it easier to understand the person’s behaviour, and what makes them feel better or worse. For example, they might feel worse if there are lots of things going on around them, if they are in pain, or if other people’s actions are affecting them. If they live somewhere too busy or too noisy (because of television or conversations, for example), this can make them feel more agitated or confused.

The environment can have a big effect on someone’s behaviour, so it’s important to keep things as calming and familiar as possible. For more information on how to adapt and make their home more suitable, see booklet 819, Making your home dementia friendly.

Sometimes people with dementia who are experiencing changes in behaviour are prescribed antipsychotic medication. These drugs should be used with caution and only considered after all other options have been tried. For more information see factsheet 408, Drugs for behavioural and psychological symptoms in dementia.

Some people with learning disabilities may already be taking antipsychotic medication for changes in their behaviour. If this is the case they should have regular reviews and the medication should only be continued where it is having a proven benefit. If you have any questions about the medication the person you care for is on taking, speak to the learning disability team or their GP.
Caring for someone with dementia and a learning disability

Supporting and caring for a person who has a learning disability and dementia can present a range of challenges. But the person may be able to continue with many activities for some time with the right support. When you are looking for ways to support the person it’s important to think about their likes and dislikes, their current and past interests and their needs. The following tips may help.

- The person you care for will already have their own ways of communicating. However, dementia can make verbal communication more difficult. When you communicate with the person it can help to use a range of non-verbal communication including gestures, body language and tone of voice.

- It can help to simplify sentences, and not ask too many questions in one go. Listen to the person carefully and give them lots of time to respond.

- Support the person’s friendships and social activities. You may need to find ways to explain to other people that the person has dementia. It can also help if you give others tips on how to support the person.

- Encourage the person to stay as independent as possible. This may mean letting them do things in their own way (as long as they are safe). It can help to use prompts and reassurance when they are doing tasks or activities that they may find difficult.

- The person you care for may already use pictorial cues (such as a picture of a toilet on the bathroom door). Using visual and pictorial cues to plan the person’s day can be really helpful.

- Routines can be really important for people with dementia just as they are for people who have learning disabilities. Try to help the person by having a routine and making sure activities happen in the same order. It can help to continue routines they are already familiar with. It’s also important to be flexible and adapt the routine to meet their needs.

- Doing life story work or creating a memory box can help the person to enjoy a meaningful activity. It can also support their relationships with others and support their sense of self. Some people with a learning disability may have already created a memory box. If so, they can still be used as an activity to engage with the person.

- The person you care for may enjoy sensory stimulation and relaxation techniques. Gentle massage and aromatherapy can be beneficial for people with dementia. Listening to music can be a rewarding and enjoyable activity if it is a style of music that the person enjoys, otherwise it can increase their agitation. The person may enjoy humming or singing along to music they enjoy, even if they find verbal communication hard.

Support after a diagnosis

After a diagnosis the person and those supporting them are likely to need support to help them live well. As well as drug treatments, there are also a range of non-drug treatments that can help a person with a learning disability and dementia.

As a carer you may find that talking to other people in a similar situation is helpful, and that it can provide you with support and ideas to help the person. The person with a learning disability and dementia may also want to meet other people with dementia. You might therefore want to see if there are any groups specifically for people with a learning disability and dementia.

Recognising and managing pain is important in people with a learning disability and dementia. Both conditions can mean that the person finds it hard to say they are in pain. It can also lead to changes in their behaviour. The person may not be able to tell you they are in pain, so look out for other signs. You are likely to know what might suggest the person is in pain, and you should look at ways to manage it. This may include pain medication (unless you have been advised against this), looking at how the person is sitting, and making sure the person has enough to eat and drink. If you are unsure ask a professional.
Where possible it is best for the person to stay in their current home with appropriate support as their dementia progresses. It’s important for them to be supported in a familiar environment with people they know for as long as it is safe.

In some circumstances the person may need to move to live in a new place. This may be because their needs can’t be met or there is a risk to themselves or others. The idea that the person you care for may have to move can be worrying and upsetting. It’s important to speak to the learning disability team about this and what options are available. If the person does need to move it’s important to adapt any new environment to make it supportive, familiar and consistent. It is also important to consider whether they need night-time support.

Our booklet, 600 Caring for a person with dementia: A practical guide acknowledges that caring can be both rewarding and demanding. It provides information and advice on lots of topics that affect carers. You might also find it helpful to read factsheet 523, Carers: Looking after yourself. Information on all aspects of dementia and care is available on our website, or to order in print.

We also provide information about the range of ways you can access support when things change.

Dementia Helpline – 0300 222 11 22

The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is open:
9am–8pm Monday–Wednesday
9am–5pm Thursday and Friday
10am—4pm Saturday and Sunday

You can also contact the Helpline by email at helpline@alzheimers.org.uk

Dementia Directory

Dementia Directory is our online dementia services directory for anyone affected by dementia in England, Wales and Northern Ireland. It has over 4,000 listings of local information, support and services. You can enter your postcode or a place name to find the services that are nearest and most relevant to you. It includes services run by voluntary or charity organisations (such as Alzheimer’s Society or Age UK), your local authority and private service providers. Each listing includes a map and clear, essential information about that service.

Visit alzheimers.org.uk/dementiaconnect

Dementia Talking Point online discussion community

Dementia Talking Point is an online support and discussion community for anyone affected by dementia. It’s a place to ask for advice, share information, join in discussions and feel supported.

Dementia Talking Point is available 24 hours a day, every day of the year.

Visit alzheimers.org.uk/talkingpoint
Other useful organisations

British Institute of Learning Disabilities
0121 415 6960
enquiries@bild.org.uk
www.bild.org.uk
BILD works to improve the lives of people with disabilities and family carers. It provides a range of published and online information including Easy Read booklets to help explain dementia to a person with a learning disability.

Down’s Syndrome Association
0333 1212 300 (helpline 10am–4pm weekdays)
info@downs-syndrome.org.uk
www.downs-syndrome.org.uk
Down’s Syndrome Association is a charity working to help people with Down’s syndrome lead full and rewarding lives. It runs a helpline and local support groups, funds research and champions the rights of people with Down’s syndrome.

Foundation for People with Learning Disabilities
020 7803 1100
fpld@fpld.org.uk
www.learningdisabilities.org.uk
Foundation for People with Learning Disabilities is a charity working to influence the government’s and local authorities’ policies and services, so that they better meet the needs of people with learning disabilities, their families and carers.

Macintyre
01908 230 100
hello@macintyrecharity.org
www.macintyrecharity.org
Macintyre provides learning, support and care for more than 1,500 children, young people and adults who have a learning disability and/or autism, at more than 150 services across England and Wales.

Mencap
0808 808 1111 (Mencap Direct helpline)
help@mencap.org.uk (England)
helpline.wales@mencap.org.uk (Wales)
helpline.ni@mencap.org.uk (Northern Ireland)
www.mencap.org.uk
Mencap is a charity providing information, advice and support services for people with learning disabilities.