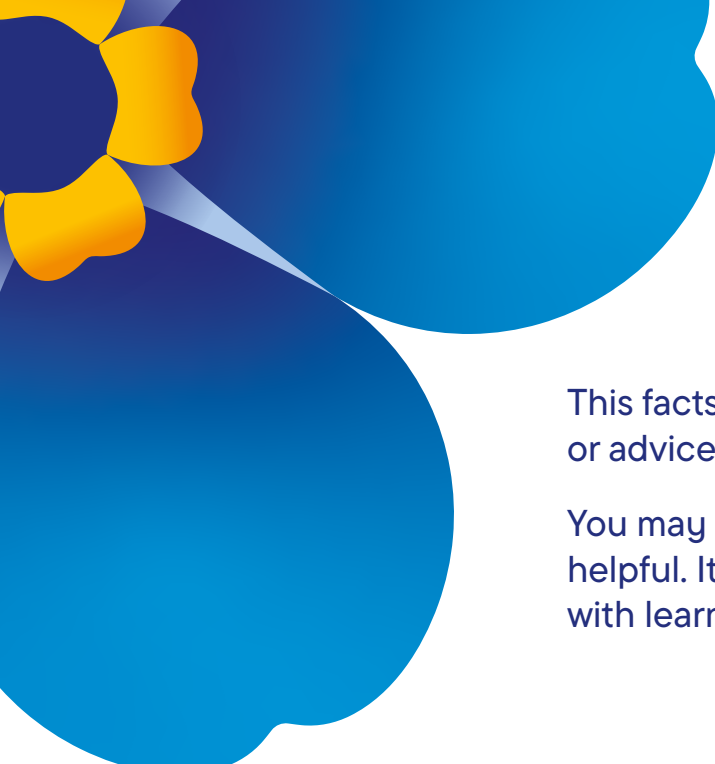


Learning disabilities and dementia



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for anyone who wants information or advice about learning disabilities and dementia.

You may also find ER1, **What is dementia?** helpful. It's an Easy Read resource for people with learning disabilities.

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1 How does dementia affect people with learning disabilities?

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People with learning disabilities are more likely to develop dementia as they get older, compared with people who do not have a learning disability.

They are also more likely to get dementia at a younger age. About 1 in 5 people with learning disabilities who are over the age of 65 will develop dementia. People with Down's syndrome have an even higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease. You can find specific information on Down's syndrome and dementia from page 8.

People with learning disabilities may find that their dementia gets worse more quickly than someone without a learning disability. This can be due to delays in getting a diagnosis because, by the time their condition is diagnosed, the person's symptoms have worsened. They are also more likely to have existing health conditions that aren't well-managed. This makes it even more important to get the right care and support.

What is a learning disability?

A learning disability reduces a person's overall intellectual ability, which makes learning new information and completing everyday tasks more difficult.

This is different from a learning difficulty, such as dyslexia. Learning difficulties relate to specific types of learning, but do not affect a person's overall intellect.

A learning disability is different for everyone and no two people will be affected in exactly the same way.

A person with a learning disability may:

- have difficulty learning and understanding new information
- take longer to develop new skills
- have difficulty interacting with other people
- need support with daily living activities.

With the right support, a person with a learning disability will be able to live a full life. Many people with a learning disability can work, live independently, have relationships and raise families.

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What is dementia?

Dementia is a group of symptoms. It's caused by different diseases that damage the brain. The symptoms get worse over time and include:

- memory loss
- confusion and needing help with daily tasks
- problems with language and understanding
- changes in behaviour.

Dementia isn't a normal part of ageing. It's caused by diseases, such as Alzheimer's disease, or events such as a series of strokes. The most common types of dementia are Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. There are many rarer diseases and conditions that can also lead to dementia.

For more detailed information on dementia see factsheet 400, **What is dementia?** or booklet 872, **The dementia guide**. Factsheet 400 is also available in Easy Read for people with learning disabilities – see factsheet ER1, **What is dementia?**

2 Recognising dementia in people with learning disabilities

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Everyone's experience of dementia is unique. For people with learning disabilities, the early signs of dementia can differ from those in people without learning disabilities. Symptoms of dementia might not be obvious because of the person's existing difficulties. This could be in the way they communicate or difficulties they have with their memory. These additional challenges can make it more difficult for a person with a learning disability to get a timely diagnosis.

What is a timely diagnosis of dementia?

A timely diagnosis is when a person can still understand what it means to have dementia. This allows them to plan ahead and make decisions while they still can. This could include things such as setting up a power of attorney or managing their money, care and support.

Knowing which symptoms to be aware of can help the person get the appropriate assessments as early as possible. There are early signs you can look out for, including:

- changes in their daily living skills
- differences in the way they approach daily tasks
- changes to their memory, reasoning or language.

You are likely to know the person that you care for best, which makes you well-placed to recognise subtle changes. This could include changes in their mood or the time it takes them to carry out certain tasks. Any changes that you, or the person's other carers, family or friends notice, can play an important part in helping to spot the early signs of dementia

If you notice ongoing changes rather than a one-off, tell the GP or learning disability team as soon as possible. They can arrange for the person to have an assessment designed to identify dementia in people with learning disabilities. See page 10 for more about diagnosis and assessments. Getting an earlier diagnosis means that you can get the right care and support sooner.

These changes can all be caused by other conditions, so it doesn't necessarily mean that the person you care for has dementia. However, all changes should be investigated by the GP or learning disability team.

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Common early symptoms of dementia

For someone with a mild learning disability, dementia may appear and progress in a similar way as someone who doesn't have a learning disability. Some common symptoms to look out for are:

- **memory loss** – such as quickly forgetting things that recently happened
- **confusion and needing help with daily tasks** – such as shopping or paying bills
- **problems with language and understanding** – including often being unable to find the right word, or having trouble following a conversation
- **changes in behaviour** – such as becoming unusually anxious or irritable.

If the person already has difficulty with some of these, look for any changes in their abilities.

For people with more complex or profound learning disabilities, the initial symptoms are likely to be less obvious or ones that are not usually associated with dementia. For example, the early symptoms may involve changes in personality and mood, difficulties in making decisions, or changes in daily living skills. This can make diagnosing dementia more difficult.

How symptoms progress

The changes you notice in the person you care for may be small to start with, but they will become more noticeable. How quickly this happens varies greatly from person to person.

As dementia progresses, the person may act in ways that seem out of character. This may include 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. For more information see factsheet 417, **Supporting a person in the later stage of dementia**.

These changes can be distressing for you and others close to the person. See page 12 for information about the support that's available.

3 Dealing with a dementia diagnosis

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A dementia diagnosis can cause a range of emotions, both for the person who has been diagnosed and for their family, friends and carers. Feeling sad, worried and angry are all common responses. Some people also feel relieved as they finally have an explanation for changes and challenges they've been experiencing.

The person may already receive social care at home or have help to live on their own. There are also experts who know about dementia and learning disabilities who can help them to understand the changes and how to live well with them. See page 12 for more about the support that's available.

As a carer, it's important that you receive support too. Close family and friends can be a good source of support. You can also speak to one of our Alzheimer's Society Dementia Support advisers on **0333 150 3456**. See page 12 for more about the support for you.

You can also find practical advice in our factsheets 524, **Understanding and supporting a person with dementia** and 523, **Carers: Looking after yourself**, and in booklet 600, **Caring for a person with dementia: A practical guide**.

Telling the person about their diagnosis

A person with a learning disability has a right to know about their dementia diagnosis. However, they may not fully understand what it is, or what it means for them.

You might find it helpful to familiarise yourself with factsheet 400, **What is dementia?** first. Then you can use our Easy Read factsheet ER1, **What is dementia?** to explain the diagnosis to the person. This factsheet has been specifically designed for people with learning disabilities.

Jenny's Diary (see page 20) is another useful resource, which uses simple language and pictures to support conversations about dementia with a person who has a learning disability.

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Tips for discussing a diagnosis

Here are some tips to help you discuss the diagnosis in a way that is sensitive and easy to understand.

- Think 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.
- Consider which details are needed at that time. You don't need to tell them everything at once.
- Slowly give the person one piece of information at a time to help them process it.
- Check that they understand what you are saying regularly.
- Use language or signs that the person is familiar with. Avoid jargon.
- Use pictures if this helps their understanding.
- Make sure everyone who talks to the person uses the same terms as much as possible.

You may also find our Easy Read factsheet ER2, **Supporting a person with dementia useful to read with the person you are caring for**. This can help them to understand what their diagnosis could mean for them, and how to manage their feelings.

Telling other people about the diagnosis

The person you care for may live with someone else with a learning disability, such as a partner, friend or other residents. Sharing the diagnosis with them can help them to understand what is happening. It will also give you a chance to talk about things they can do to help, for example supporting the person with hobbies.

Make sure you check with the person before you share their diagnosis. If they don't have capacity to make the decision, you should consider what is in their best interest.

Agreeing a care plan

After the dementia diagnosis, the care or multidisciplinary team will agree a care plan or update an existing plan, with the person and anyone supporting them. The aim of this plan is to help them to live well with dementia. The team will also agree when the plan should be updated, including checking for and looking into any changes in the person's health, behaviour or daily living skills.

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

Planning for the future

Planning for the future or ‘advance care planning’ of the person you care for can be very difficult. If possible, encourage and support the person to think about how they would like to be cared for as their dementia progresses. This could include decisions about where the person wishes to live, as well as future medical treatment. It’s best to make these decisions soon after a diagnosis, so that you can put plans in place.

By law, the person with dementia should be involved in decisions about their future care as much as they are able to be. Their ability to make decisions depends on their individual situation, so even if they do not have capacity to make some decisions, they may still have capacity to make others. If someone else is making decisions for the person, it’s important these are in the person’s best interest and that they are the least restrictive option. For more information see factsheet 460, **Mental Capacity Act 2005**.

The person may already have 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 is unable to make decisions about these things 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 is no longer able 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**.

You might find it useful to read booklet 1510, Planning ahead and factsheet 472, **Lasting power of attorney**. For information about advance statements and advance decisions in England and Wales see factsheet 463, **Advance decisions and advance statements**, and for laws that relate to Northern Ireland see factsheet NI467, **Financial and legal tips**.

See booklet 872, **The dementia guide** for more information on making decisions about the future.

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4 Dementia and Down's syndrome

Almost all people with Down's syndrome will develop changes in the frontal lobe of their brain as they get older. This can cause similar symptoms to dementia, such as difficulties with decision making and planning, and changes in behaviour. However, not all people with Down's syndrome will go on to develop dementia

The reasons why people with Down's syndrome are at a higher risk of Alzheimer's disease are not well-understood. It is thought to be due to chromosome 21, which most people with Down's syndrome have an extra copy of. This leads to a build-up of a protein, which forms plaques on the brain. These plaques are a feature of Alzheimer's disease.

Symptoms

People with Down's syndrome may have similar symptoms to those described on page 4. However, there may be some differences, such as changes in the person's behaviour and personality. They might become less willing to co-operate (for example, with daily tasks around the home). Or they might become stubborn, irritable or withdrawn.

The most common sign of dementia in older people is memory loss. As a person with Down's syndrome may already have difficulties with their short-term memory, this symptom of dementia can easily be missed.

People with Down's syndrome may experience epilepsy or fits. If a person with Down's syndrome in later life begins to have fits, or experiences them more than usual, this could be a sign of dementia. Speak to the GP straightaway if you have any concerns about the person you care for. If the person has serious fits or seizures, it's possible their health will get worse more quickly.

If the person you care for has Down's syndrome, they are also more likely to have sight or hearing loss, depression, and an underactive thyroid. Dementia can complicate all of these conditions. If you have any concerns or worries, speak to their GP or community learning disability nurse.

Annual health checks

Everyone who has Down's syndrome should have a baseline test by the age of 30. This test is important because, as the person gets older, it establishes their level of functioning. This includes their skills, abilities and personality. Having a baseline makes it easier to spot possible health changes, including dementia, in the future.

An adult with Down's syndrome should have a health check with their GP once a year, unless changes are noted sooner.

The GP checks:

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

Following this, their GP might make a referral to a specialist.

As part of the health check, the person should have an agreed health action plan. This will give you advice on how you can help them to stay healthy.

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5 Assessment for dementia

The assessment for dementia is best done by 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
- community learning disability nurse or an occupational therapist
- clinical psychologist.

The multidisciplinary team should speak to the person with a learning disability where possible, as well as their main carer and any care service staff who know the person well. This helps them to find out how the person feels about things and how they communicate.

The assessment will include the following stages.

- **A detailed look at their personal history** – This should include any important changes in the person's life, such as moving home, the recent death of someone close to them, or changes to their carer. This gives more information about how the person may be feeling – and why. It helps to rule out other underlying causes for changes in behaviour or abilities, such as stress or depression.
- **A full health assessment** – This should rule out any physical problems that could cause the person's changes in behaviour or cognitive problems. There are lots of conditions that have similar symptoms to dementia, but that are treatable – for example an underactive thyroid, which is common in people who have Down's syndrome.

Any medicines they are taking should also be reviewed as part of this assessment. And their vision and hearing should be tested too because sensory impairments are more common in people with learning disabilities.

- **Cognitive and mental state assessments** – There is no single test to diagnose dementia. However, there are a range of screening tools designed to help healthcare professionals diagnose dementia in people with Down's syndrome. The team will observe things like the person's alertness, mood and their orientation to time, place and person. They will also consider the person's mental health and their ability to carry out day-to-day activities.

Any assessment should involve the person as much as possible. If this isn't possible, the person's main carer, who may be you, could be asked to complete an assessment that outlines changes in the person.

The team of specialists will then review the assessments and use the results alongside other details they know about the person to inform any diagnosis. A diagnosis should never be made solely on the cognitive or mental state assessments. The same assessments should be used each time the person is assessed. The team can then compare these and see how the person's functioning has changed over time.

Special investigations

Special investigations are used to try to rule out other health conditions, such as a brain tumour or a brain bleed. They are also used when doctors are unsure whether the person has dementia from other assessments. An example of a special investigation is a brain scan. These investigations can be distressing or confusing for the person though, and so may not always be appropriate or possible to complete.

Even with a thorough assessment for dementia, it will not always be possible to make a clear diagnosis of dementia in a person with Down's syndrome. Instead, it may be necessary to wait and monitor how the person gets on. Repeating the assessment for dementia several months later is usually the next step. This is why a baseline assessment of the person is important.

Looking at where the person lives (environmental assessments)

An environmental assessment involves someone checking that the person's home is suitable for them. If it isn't, they may have difficulties with daily living that may be mistaken with dementia symptoms. The assessment should look at:

- how appropriate it is for their current and changing needs
- whether the level and quality of support available, both throughout the day and night, matches what is required as dementia progresses
- whether the person takes part in appropriate, personalised and meaningful daytime activities.

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6 Getting treatment and support

For a person to live well with dementia they need a range of appropriate treatment, support and activities. A person with a learning disability and dementia may see a psychiatrist specialising in learning disabilities, as part of their treatment. They may also get support from staff from the learning disability services. As well as medicines, the person's treatment may involve other types of therapies.

Treating the symptoms

At present, there is no cure for dementia. However, there are medicines for certain types, such as dementia caused by Alzheimer's disease. These medicines may ease symptoms or prevent them from getting worse for a time for some people. The medicines don't slow down or stop the underlying disease from causing damage to the brain. They also will not increase a person's life expectancy. For more on this, see factsheet 407, **Medicines to help thinking and memory.**

People with a learning disability and dementia may be prescribed one of these medicines. Donepezil (also known as Aricept) is one of the most common. These medicines will not be effective for everyone, however there is some evidence that they may improve the quality of life for some people and for those supporting them.

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

Memantine is another medicine used to treat dementia symptoms. This can be effective for people with learning disabilities and dementia. For people with Down's syndrome and dementia, the current evidence suggests it will not work, although the doctor might suggest trying this.

Coping with changes in behaviour

The person you care for may begin to behave in ways that are distressing to you and others. Their dementia may also affect the way they perceive the world around them. Understanding this can help you to recognise 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 you can put strategies in place to help.

An important part of finding ways to manage or prevent distressing behaviours is to involve others who help with the person's care and support. It's important for people with learning disabilities and dementia to have consistency. As far as it is possible, 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 distressed or confused if:

- there are lots of things going on around them
- they are in pain or discomfort
- other people's actions are affecting them
- they live somewhere too busy or too noisy, for example because of television or loud conversations

See factsheet 525, **Changes in behaviour** for more information.

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

Sometimes, people with dementia who are experiencing changes in behaviour are prescribed antipsychotic medicine. They should be used with caution and only considered after all other options have been tried.

Some people with learning disabilities may already be taking antipsychotic medicine for their behaviour. If this is the case, they should have regular reviews. The medicine should only be continued where it is having a proven benefit. If you have any questions about the medicine the person you care for is taking, or if a new medicine for one condition is making another worse, speak to the learning disability team or their GP. For more information see factsheet 408, **Drugs for behavioural and psychological symptoms in dementia**.

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Recognising and managing pain

As with anyone, recognising and managing pain is important in people with a learning disability and dementia. Pain or discomfort can be caused by an injury, an illness or a medical condition. Both dementia and learning disabilities can mean that the person finds it hard to say that they are in pain, so it's important to be aware of signs.

You are likely to know what might suggest the person you care for is in pain or feeling uncomfortable, and the best ways to support them. This may include looking at how the person is sitting, making sure they have enough to eat and drink, or using pain medication (unless you have been advised against this).

Sometimes, when a person is in pain, it can also lead to changes in their behaviour. Speak with the GP if you have any concerns as they can investigate whether there is a physical or medical cause for any discomfort or pain.

Getting support after a diagnosis

Where possible, it is best for the person to stay in their current home with appropriate support as their dementia progresses. It's important that this is 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 a new environment. This may be because their needs can't be met where they live, or because 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 may need night-time support in the future.

Support from other people

The person you care for may enjoy being with other people with a learning disability and dementia. As a carer, you may also 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. You can search for groups for both of you in your area at alzheimers.org.uk/dementi DIRECTORY.

Online discussion forums can also be a good way of talking with other people and getting practical suggestions. Our online community Talking Point – alzheimers.org.uk/talkingpoint – is just one example that can help you.

Booklet 600, **Caring for a person with dementia: A practical guide** provides information and advice for carers. You might find it helpful to read factsheet 523, **Carers: Looking after yourself** too.

It's important to seek support if you need it and to talk to someone about the situation and how you are feeling. This might be a friend, family member, your GP or a trained counsellor. You can also call Alzheimer's Society Dementia Support advisers on **0333 150 3456**.

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7 Caring for someone who has a learning disability and dementia

With the right support, the person you care for may be able to continue with their daily routines, activities and hobbies for some time. Think about their personality, their likes and dislikes, as well as their current and past interests and needs. Developing a life story book or box can be helpful if appropriate photographs or memorabilia are available. This will help you to tailor care and support to them.

To help others involved in the person's care, you may find it helpful to complete 1553, **This is me** together. This simple leaflet helps everyone understand much more about the person's background, preferences and routines, which can help them deliver care that is tailored to their needs. The following tips may also help.

Communicating effectively

The person you care for will already have their own ways of communicating. You should continue to communicate in a way that suits them. Dementia can make verbal communication more difficult.

- It can help to use a range of non-verbal communication. This includes gestures, body language and tone of voice. For more information see factsheet 500, **Communicating**.
- Keep sentences short and simple.
- Avoid asking too many questions or giving too much information at once.
- Listen to the person carefully and give them lots of time to respond.
- Consider using pictures or photos as prompts for conversation or to help the person understand what is being said.

Maintaining independence and routines

Routines are really important for people with dementia, just as they are for people with learning disabilities. Encouraging independence can also help the person's confidence and sense of identity.

- Support the person's friendships and social activities. It can also help if you give their friends tips on how to support them. Our Easy Read factsheet ER2, **Supporting a person with dementia** includes some useful suggestions.
- Encourage the person to stay as independent as possible. Let 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. Adapting tasks can also help.
- Picture cues (such as an image of a toilet on the bathroom door) can be helpful and the person may already use these. Photos of carers and their names can also be helpful to have in the home.
- Having a familiar routine and making sure activities happen in the same order can really help a person with a learning disability and dementia. It's also important to be flexible and adapt the routine to meet their needs if necessary.

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Meaningful activities

Meaningful activities can help the person you care for to maintain their relationships with others and support their sense of self.

Create a memory box or try life story work. If the person you care for already has a memory box, this can still be used as an activity to engage with them, provided that it does not cause distress or trigger distressing memories.

Consider trying sensory stimulation and relaxation techniques – for example, gentle massage and aromatherapy can be beneficial for people with dementia. Listening to music can also be an enjoyable activity if it is a style of music that the person enjoys, otherwise it may increase agitation. The person may enjoy humming or singing along to music they enjoy, even if they find verbal communication hard.

For more information on activities, including life story work, memory boxes and sensory stimulation, see booklet 77AC, **The activities handbook**.

Other useful organisations

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British Institute of Learning Disabilities (BILD)

0121 415 6960

enquiries@bild.org.uk

www.bild.org.uk

BILD works to improve the lives of people with disabilities, their friends 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.

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersuk.org

www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Carers UK provides information and advice to carers about their rights and how to access support.

Dementia UK

0800 888 6678 (9am–9pm Monday–Friday, 9am–5pm

Saturday and Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK is committed to improving quality of life for all people affected by dementia. It provides Admiral nurses who are mental health nurses specialising in dementia care.

Down's Syndrome Association

0333 1212 300 (10am–4pm Monday–Friday)

info@downs-syndrome.org.uk

www.downs-syndrome.org.uk

Down's Syndrome Association helps people with Down's syndrome to lead full and rewarding lives. It runs a helpline and local support groups. The Association also funds research and champions the rights of people with Down's syndrome.

Foundation for People with Learning Disabilities

fpld@fpld.org.uk

www.learningdisabilities.org.uk

Foundation for People with Learning Disabilities works to influence local authorities and service providers, so they better meet the needs of people with learning disabilities, their families and carers.

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Jenny's Diary

www.learningdisabilityanddementia.org/jennys-diary

Jenny's diary is a research-based booklet that has been developed to help people with learning disabilities understand dementia. It is freely available to download.

MacIntyre

01908 230100

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.

Mencap

0808 808 1111 (Learning disability helpline, 9am–3pm

Monday–Friday)

helpline@mencap.org.uk (England)

www.mencap.org.uk

Mencap provides information, advice and support services for people with learning disabilities.

Mencap NI

0808 808 1111 (Learning disability helpline, 9am–3pm

Monday–Friday)

helpline.ni@mencap.org.uk (Northern Ireland)

www.mencap.org.uk

www.northernireland.mencap.org.uk

Mencap Wales

0808 8000 300 (Learning disability helpline, 9am–3pm

Monday–Friday)

helpline.wales@mencap.org.uk (Wales)

www.wales.mencap.org.uk/about-mencap-cymru



Factsheet 430
Last reviewed: November 2022
Next review due: November 2025


Reviewed by: Dr Karen Watchman, Senior Lecturer,
University of Stirling and Jane Nickels MA, Registered Nurse
Learning Disabilities

To give feedback on this factsheet, or for a list of sources,
please email publications@alzheimers.org.uk

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information

About dementia.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



**Alzheimer's
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Together we are help & hope
for everyone living with dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804

enquiries@alzheimers.org.uk
alzheimers.org.uk

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