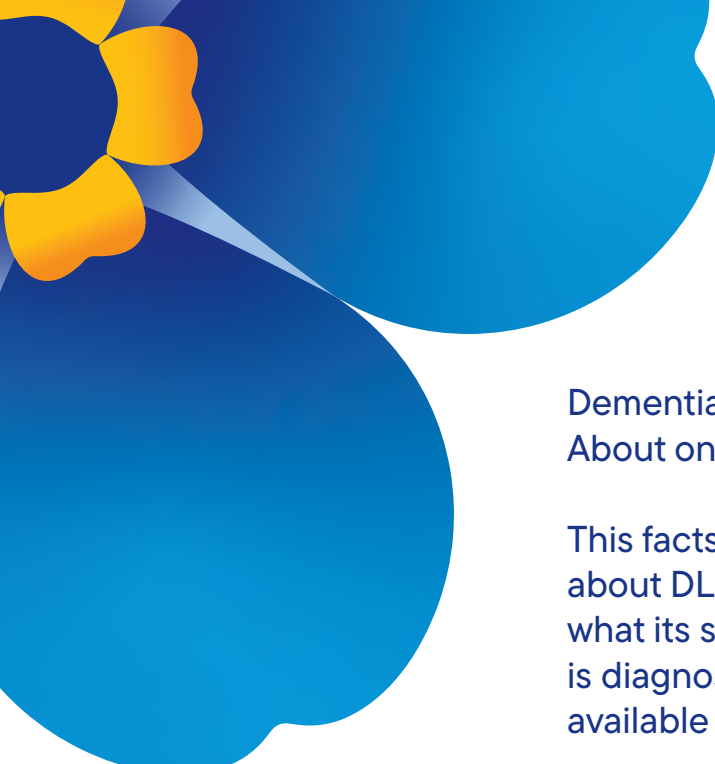


# What is dementia with Lewy bodies (DLB)?



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Together we are help & hope  
for everyone living with dementia



Dementia with Lewy bodies (DLB) is a type of dementia. About one in ten people with dementia has DLB.

This factsheet is for anyone who wants to know more about DLB. It explains what DLB is, who gets it and what its symptoms are. It also describes how DLB is diagnosed, as well as the treatment and support available for a person with DLB.

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# 1 What is dementia with Lewy bodies (DLB)?

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Dementia is caused by different diseases that affect the brain. Dementia with Lewy bodies (DLB) is caused by Lewy body disease. In this disease, tiny clumps of proteins – known as Lewy bodies – appear in the nerve cells of the brain. Lewy bodies are named after FH Lewy, the German doctor who first identified them.

It is not yet known why Lewy bodies develop in the brain or exactly how they cause dementia. But we do know that Lewy body disease:

- can cause different symptoms depending on what parts of the brain have the biggest build-up of faulty proteins
- reduces the levels of important chemicals needed to send messages around the brain
- breaks the connections between nerve cells, eventually causing these cells to stop working
- usually develops over a period of many years – typically when a person is approaching old age. Lewy bodies can be developing in the brain for a long time before any symptoms show.

Having Lewy body disease doesn't mean that a person's dementia is only caused by the build-up of Lewy bodies in their brain. Many people with DLB also have a build-up of other proteins that cause Alzheimer's disease. This is common in people over about 80 years old. For people with both DLB and Alzheimer's, dementia symptoms are often more severe and progress more quickly.

**Parkinson's disease is also caused by a build-up of Lewy bodies in the brain. DLB has a lot of symptoms in common with Parkinson's disease. Both cause problems with thinking, movement, mood and how well the body works.**

**In DLB, the symptoms of dementia begin before or around the same time as the person develops problems with movement. For people with Parkinson's disease, symptoms of dementia often develop many years after the movement problems begin.**

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## 2 Who gets DLB?

Around 5% of people with a diagnosis of dementia are recorded as having DLB, but there is good evidence that the condition is under-diagnosed. Scientists think DLB may account for up to 20% of all dementia.

DLB affects men and women roughly equally. As with most other types of dementia, DLB becomes increasingly common over the age of 65. It can also affect people younger than this.

There is not much evidence that anything we might be exposed to during our lives increases the risk of DLB. Having a traumatic head injury (or repeated injuries) may increase the risk of developing Parkinson's disease later in life, but it's not known whether this also applies to DLB.

Almost all people who develop DLB have a 'sporadic' form, which means that the main cause is unknown. Some genes may increase the risk of developing DLB. To find out more about the role that genes play in DLB see factsheet 405, **Genetics of dementia**.

## 3 Symptoms

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Everyone experiences dementia differently. Alzheimer's disease and DLB can both cause problems with staying focused and decision-making. Other symptoms of both conditions include memory loss and difficulties with the way someone sees things around them.

Other common symptoms of DLB include hallucinations, problems staying fully awake, difficulties with movement and disturbed sleep. These are not usually seen in Alzheimer's disease. The way someone is affected by DLB will depend partly on where the Lewy bodies are in the brain:

- Lewy bodies at the base of the brain are closely linked to problems with movement. These are the main feature of Parkinson's disease.
- Lewy bodies in the outer layers of the brain are linked to problems with mental abilities, which is a feature of DLB and other types of dementia.

When DLB starts to affect someone, early symptoms may not cause too many difficulties. Gradually though, these get worse and cause problems with everyday living. These are described in more detail in the following sections.

### Mental abilities and alertness

Problems with attention and mental abilities are common in DLB:

- A person may become confused and what they say may not make sense. These problems are likely to vary a lot throughout the day, from hour to hour or even over the course of a few minutes.
- A person may have difficulty staying alert during the day. They may become less aware of what's going on around them and appear to 'switch off'.
- A person may have difficulties judging distances and seeing objects clearly in three dimensions. For example, the person may not be able to recognise the edge of a step on the stairs and know to change how they approach this.
- A person may struggle with planning, organising and making decisions.
- Day-to-day memory is often affected in people with DLB, but usually much less in the early stages of Alzheimer's disease, where it is the main feature.

Some people also experience depression, anxiety or apathy. For more information see factsheet 444, **Supporting a person who has depression, anxiety or apathy.**

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**My mother is experiencing hallucinations of children and animals.**

Family member  
of a person with  
dementia



### Hallucinations and delusions

A common early symptom for people with DLB is visual hallucinations (seeing things that are not there). The person might describe seeing people or animals. For some people this is disturbing. Hallucinations in other senses – such as hearing, smell or touch – can also happen in DLB, although these are less common.

Visual hallucinations are one of the reasons why a person with DLB may stop driving, because this is no longer safe. For more information see factsheet 439, **Driving and dementia**.

Most people with DLB also have delusions (persistently thinking things that are not true) at some stage.

For more information on hallucinations and delusions see factsheet 527, **Changes in perception**.

### Movement problems

Up to two-thirds of people with DLB have movement difficulties when they are diagnosed, and this increases as DLB progresses. The movement-related symptoms of DLB are similar to those of Parkinson's disease. They include slow and stiff movement of limbs. Their facial expressions may also be limited.

The person's posture may become increasingly stooped, and they may shuffle when they walk. They may also have difficulty with their balance and their limbs may sometimes tremble. This, combined with difficulty seeing objects properly, can make them prone to falling and getting hurt.

### Sleep problems

Not sleeping well is a common symptom of DLB and can start many years before a person is diagnosed. They may fall asleep very easily during the day, but then have restless, disturbed nights. If the person has rapid eye movement (REM) sleep behaviour disorder, they may physically act out their dreams. This kind of very disturbed sleep is a feature of DLB (and Parkinson's). See 'Support for sleep disturbance' on page 10.

## Problems with how the body works

DLB affects the body in many ways that don't relate to either dementia or movement. These can include the things we do automatically, but don't usually think about. For example, DLB can cause problems with:

- constipation
- problems passing urine – for example, needing to pee often or in a hurry, or not being able to stop it coming
- erectile dysfunction (not being able to get or keep a firm erection)
- losing some sense of smell or taste (or both)
- low blood pressure when standing up – this can cause dizziness and fainting.

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# 4 Getting a diagnosis of DLB

Having a diagnosis of dementia can allow a person to get the support they need to live well. It is important to know the specific type of dementia a person has, especially if it's possible they may have DLB. This is because the medicines used to treat hallucinations and delusions in other types of dementia can cause a bad reaction in a person with DLB.

DLB can sometimes be difficult to spot, and a diagnosis should be made by a specialist with experience of the condition. People with DLB are often mistakenly diagnosed as having another type of dementia, such as Alzheimer's disease.

DLB may be mistaken for delirium – particularly if the person is first seen by medical staff during an emergency admission to hospital.

## Assessment

During the assessment, the doctor will talk to the person and someone who knows them well. They will ask about the person's medical history, when their symptoms started, and how well they have been able to get on with daily life.

The doctor may do some blood tests to rule out other causes of the person's symptoms, such as a low level of vitamins in the body or hormone problems. They should check the person's eyesight and hearing, as problems with these can play a part in the person's symptoms.

The doctor should also check the person's medications. Some medicines used to treat depression, allergies or incontinence can cause confusion.

The person will be asked to complete tests or activities designed to show if they are having problems with thinking and perception. How well a person with DLB functions can vary a lot from day to day. These tests can sometimes miss symptoms if the person does one when they are having a 'good day' and can concentrate much more than on a 'bad day'.

The doctor may also look at a person's muscle stiffness and balance to see if the disease has affected their movement. If the person is showing any movement-related symptoms, they may be referred to a neurologist (who can help with movement problems).

For more information see booklet 78DD, **Diagnosing dementia: A practical guide to assessment.**



## Brain and heart scans

If the person shows signs of DLB, they may have a brain scan to help confirm the diagnosis.

A CT or MRI scan may rule out other brain conditions, such as a brain tumour, excess fluid or a bleed on the brain. If it is still not possible to make a diagnosis, a more specialised scan of the brain can be carried out. This can show the difference between DLB and other types of dementia. Doctors may scan the nerve cells in a person's heart, as these can show similar changes to those in the brain of a person with DLB.

If there is still doubt, another type of brain scan can confirm a diagnosis of DLB if it shows loss of a particular type of cell (dopamine nerve cells) at the base of the brain.

For support for a person with a diagnosis of DLB, see booklet 872, **The dementia guide.**

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# 5 Treatment and support

There is no cure for DLB. The person's care and treatment should support them to live as well as possible. A person with DLB should be offered both medicines and non-medicine treatments to help them to keep doing things for themselves.

**It is important to regularly see the GP, who can refer a person with dementia to the right support when they need it. For more information see factsheet 425, How the GP can support a person with dementia.**

## Treatments without medicines

There are many ways to help someone to live well with DLB that don't involve medicines. These include information, advice, support, therapies and activities. We have a range of information that can help, and the GP and memory service can give advice too.

After a diagnosis, both the person and their carer will need support. This should give them the chance to talk things over with a professional, ask questions and think about the future. It's also important to get information on planning ahead, where to get help and how to stay physically and mentally well. For more information see booklet 1510, **Planning ahead**.

Ways to improve and maintain general wellbeing, mental abilities and mood include:

- socialising with friends or family, or a local group – this can be in person or remotely
- keeping a routine
- talking therapies, such as counselling, which can help someone come to terms with their diagnosis or discuss their feelings
- cognitive behavioural therapy (CBT), which may be offered if the person develops depression or anxiety
- cognitive stimulation therapy, which involves doing themed activity sessions over several weeks
- cognitive rehabilitation, in which a person is helped to retain skills and cope better. There is also lots that can be done at home to help someone with dementia remain independent and cope with memory loss. For more information see factsheet 429, **Using equipment and making adaptations at home** and booklet 819, **Making your home dementia friendly**

- life story work, in which the person is encouraged to share their life experiences and memories
- reminiscence work, usually enjoyed as a person's dementia progresses.

Other popular activities include music, singing or art. It is vital that people with DLB stay as active as they can – physically, mentally and socially. Taking part in meaningful activities is enjoyable and leads to increased confidence and self-esteem.

### Treatments for agitation and distress

DLB can sometimes cause a person to become agitated and distressed. This may be because they are having hallucinations or delusions, they are very tired and emotional (from sleep problems), or they may be struggling to understand what is going on around them. Positive interactions with other people, or activities matched to the person's abilities and interests, can help. For example, they may benefit from music therapy, physical exercise and hand massage. For more information on ways to help the person stay engaged and active see booklet 77AC, **The activities handbook**.

### Physical health problems

The person may have an unmet need that they are struggling to understand or communicate to others, such as being in pain or discomfort. Any physical health problem – such as dehydration, an infection or constipation – can cause someone with DLB to become more confused and disorientated. This can make a person become restless, engage in repetitive or obsessive behaviour, or shout. In some cases, a person with DLB may lash out in frustration or become violent. It is important that everyone supporting the person with dementia, and the person themselves, are safe from harm.

For more information see factsheets 500, **Communicating**, 525, **Changes in behaviour** and 509, **Aggressive behaviour**.

### Support for hallucinations and delusions

If someone is having visual hallucinations or delusions, it is unhelpful to try to convince them that what they are seeing is not there, or that what they believe is untrue. Instead, carers can offer them reassurance, remind them that they are there to support the person, and try gently distracting them.

Hallucinations that are not distressing to the person may not need to be stopped. Some may even be comforting, such as the sight of a friend or family member sitting by the bed.

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A couple evenings later mum pulled me aside and asked, who is that lady walking through our house? Again, only me, mum and my brother were at home. I told her that maybe she was getting sleepy and dreaming with her eyes open.

Family member of a person with dementia

”

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It is important to get a person's eyesight and hearing checked regularly. Support them to keep their glasses or hearing aids clean and working properly. Problems with these can make difficulties with seeing or sensing things worse.

For more information on hallucinations and delusions, including practical tips to support the person, see factsheet 527, **Changes in perception**.

### Support for movement problems

A person with movement problems will often benefit from support from an occupational therapist or physiotherapist. They can help the person to move and stay independent, as well as advise on aids and adaptations in the home. For more information see factsheet 429, **Using equipment and making adaptations at home**.

A speech and language therapist is often helpful if the person develops problems with swallowing or speaking. The GP or community nurse can make a referral.

If the person has had falls or is worried about falling, the GP may refer them to a falls prevention service. Their risk of falls may be reduced by strength and balance exercises, an eyesight test or a medication review. It is also a good idea to make their home safer – for example, improving light levels, decluttering and removing trip hazards.

For more information see booklet 819, **Making your home dementia friendly** and 1502, **Keeping safe at home**.

### Support for sleep disturbance

A lack of good quality sleep is one of the most difficult problems for a person with DLB. It can make other aspects of the condition much harder to cope with.

There are ways to help have more restful nights. Increasing levels of physical activity during the day, having a regular bedtime and getting-up time, and reducing daytime napping can all help.

It can also help to avoid alcohol, caffeine and nicotine close to bedtime, and to keep the bedroom quiet, well-ventilated and at a comfortable temperature – cool but not cold.

Because some people with DLB act out their dreams, they may move their limbs violently and accidentally injure themselves or a partner. Some partners sleep in separate beds. Practical steps can be taken to make the area around the bed safe – remove sharp objects and put a mattress alongside the bed in case the person falls or jumps out in their sleep.

For more information see factsheet 534, **Understanding sleep problems, night-time disturbance and dementia**.

## Treatments with medicines

Treatment of DLB symptoms with medicines often takes some trial and error to get right. This is because everyone responds differently to medication, and there is not much evidence about what works well.

Medicines for improving movement may worsen mental abilities and can make hallucinations worse. There can also be serious risks for a person with DLB if they are treated with medications known as 'antipsychotics'.

**If a person goes into hospital or sees a new doctor, the person or their family should check that medical staff know that the person has DLB (not just 'dementia'). This diagnosis should be clearly recorded in the person's notes. This is important because people with DLB can have a serious reaction to antipsychotic medication that is usually safe for people with other types of dementia to take.**

### Medicines for concentration problems

Some medicines can help to manage symptoms for a while. These medicines may help some people with DLB improve their attention and alertness, as well as help with problems such as thinking more slowly. They are:

- donepezil
- rivastigmine – which can also be given as a patch on the person's skin
- memantine – often in addition to donepezil or rivastigmine.

Rivastigmine and, less often, donepezil may also reduce hallucinations and delusions in people with DLB.

It is recommended that a person keeps taking these medicines throughout their dementia if they seem to be helping. However, some people may find that these medicines don't work for them, or their side effects are not worth the small benefits. If so, they should tell their doctor – they may suggest switching to another medicine or focusing more on treatment without medicines.

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### Antipsychotic medicines

Antipsychotic medicines are sometimes prescribed for hallucinations or delusions in DLB. However, they can have dangerous side effects and rarely benefit people with dementia. For this reason, they should not be given to a person with DLB unless there is an immediate risk of harm to the person or those around them, or if the person is in distress. Treatments without medicines should also have been tried before antipsychotic medication.

These medicines should be given in very small doses by a specialist, and the person must be monitored closely for problems while they are taking them. They should be taken off the medicines as soon as possible.

Up to half of people taking these medicines have severe reactions, with difficulty moving (including stiffness), becoming more confused, and being unable to perform tasks or communicate. They also significantly increase the risk of the person having a stroke or dying suddenly.

### Medicines for sleep problems

A person with DLB should talk to their GP about sleep problems. Medicines such as melatonin or clonazepam can be effective short-term treatments for some sleep problems. Melatonin may need to be taken for longer periods if the person has REM sleep behaviour disorder. Clonazepam may worsen the person's mental abilities and alertness and so tends to be used only for shorter periods. For more information see factsheet 534, **Understanding sleep problems, night-time disturbance and dementia**.

### Medicines for movement problems

The medicine levodopa, used to treat Parkinson's disease, is sometimes given to people with DLB who have movement problems. Levodopa is less effective in DLB than in Parkinson's disease.

It improves falls and movement problems in around one-third of people with DLB. Levodopa can also increase confusion, reduce mental abilities such as alertness and attention, or make hallucinations worse.

## Support in the later stages of DLB

DLB is a progressive condition, so over time symptoms get worse. This is generally over a period of several years.

As the disease progresses, the person may start to have more problems with their day-to-day memory. They can also become much more easily upset or distressed, resulting in agitation, restlessness or shouting out.

Because of movement problems, walking will get slower and less steady. This can greatly increase the risk of falling and serious injury.

In the later stages of DLB, many people also have problems with eating and drinking. Chewing and swallowing may become more difficult, and the person's stomach and gut may not move food around the body properly, leading to a loss of appetite as well as nausea and discomfort. Speech and swallowing problems may lead to chest infections or a risk of choking.

Eventually, someone with DLB is likely to need a large amount of personal care. It is difficult to predict how quickly the condition will progress over time. The person will also need personal care sooner if they have other health conditions that affect their ability to function on their own. For more information see factsheet 458, **The progression and stages of dementia**.

Planning for end of life is important for anyone who has a life-limiting condition, such as DLB. It can be upsetting to think about, but planning ahead can help to meet the person's needs at the end of their life. For information for a person living with dementia, see booklet 1510, **Planning ahead**, and for information for carers see factsheets 531, **End of life care** and 417, **Supporting a person in the later stage of dementia**.

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## Other useful organisations

**The Lewy Body Society****0800 888 6678 (helpline answered by Dementia UK****Admiral nurses, 9am–9pm Monday–Friday,****9am–5pm Saturday–Sunday)****01942 914000 (information)****info@lewybody.org****www.lewybody.org**

The Lewy Body Society aims to raise awareness of DLB for the public and educate medical professionals and decision-makers about all aspects of the disease. It also supports research into the disease.

**Parkinson's UK****0808 800 0303 (helpline, 9am–6pm Monday–Friday,****10am–2pm Saturday)****hello@parkinsons.org.uk****www.parkinsons.org.uk**

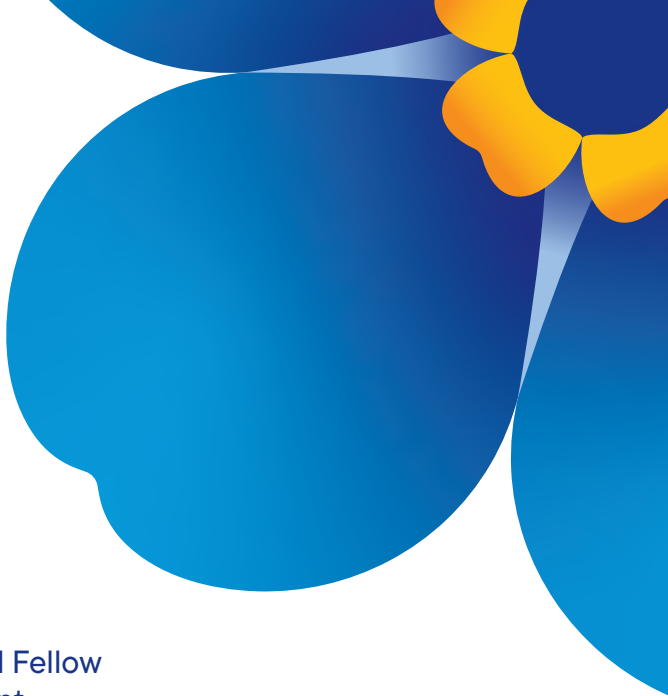
Parkinson's UK provides information, advice and support for people with Parkinson's disease. It can put people in touch with their nearest branch, offering local support and social contact for those with Parkinson's and their families.



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This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto: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](http://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](http://alzheimers.org.uk/donate)**



*Patient Information Forum*



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia

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