

# What is dementia with Lewy bodies?



**Alzheimer's  
Research  
UK**

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Information in this booklet is for anyone who wants to know more about dementia with Lewy bodies (DLB). This includes people living with DLB, their carers, families and friends. The booklet gives an introduction to DLB. It provides an overview of the causes, symptoms and treatments.

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This information does not replace any advice that doctors, pharmacists or nurses may give you but provides some background information that we hope you will find helpful.

The booklet was updated in December 2019 and is due to be reviewed in December 2021. Please contact us if you would like a version with references or in a different format.

## What is dementia with Lewy bodies?

The word dementia is used to describe a group of symptoms. These include memory loss, confusion and changes in language, vision and behaviour that affect day-to-day life.

There are a number of different causes of dementia, with Alzheimer's disease being the most common.

Dementia with Lewy bodies (DLB) is the third most common type of dementia. For every 100 people with dementia, around 10-15 will have DLB. This means roughly 100,000 people in the UK are likely to have this form of dementia. DLB can also occur with other types of dementia, such as Alzheimer's disease; this is called 'mixed dementia'.

DLB is caused by small round clumps of protein that build up inside nerve cells in the brain. One of these proteins is called alpha-synuclein and the clumps it forms are called Lewy bodies. Lewy bodies damage the nerve cells and affect the way they communicate.

In DLB, the nerve cells that are affected by Lewy bodies are in areas of the brain that control thinking, memory and movement.

## DLB, Parkinson's disease and Parkinson's disease dementia

DLB is closely related to Parkinson's disease. Lewy bodies also cause the damage that leads to movement problems in Parkinson's. People with Parkinson's are more likely to go on to develop dementia, which is known as Parkinson's disease dementia (PDD).

DLB and PDD can affect people in very similar ways. If dementia symptoms appear before or at the same time as people start to have movement problems, a diagnosis of DLB is likely to be given. If movement problems are present for a year or more before signs of dementia appear, a diagnosis of PDD is likely to be given.




## Symptoms


Dementia with Lewy bodies can cause common dementia symptoms, including problems with memory and thinking skills.





However, there are some more specific symptoms associated with the disease. Some of these symptoms are also seen in PDD.


### These symptoms include:


 **Alertness**  
Changes in alertness and attention, and periods of confusion, that may be unpredictable and change from hour-to-hour or day-to-day.

 **Movement problems**  
Parkinson's-type symptoms such as slower movements, stiffness in the arms and legs, and shaking or trembling.

 **Visual hallucinations**  
Seeing things that are not really there, e.g. people or animals. These often happen repeatedly and are realistic and well-formed.

 **Stability**  
Unsteadiness and falls.

 **Sleep disturbances**  
Vivid dreams, shouting out or moving while sleeping which can disrupt sleep, and may cause injury.

 **Sense of smell**  
Problems detecting smells.

DLB and PDD are progressive conditions which means that symptoms get worse over time. As the disease progresses, people will need more help eating, moving, dressing and using the toilet.

The diseases can progress slowly over several years, but the speed of change and type of symptoms can vary from person to person.

## Diagnosis

It is important to get the right diagnosis so that the right treatments and help can be given.

If you are worried about your health or someone else's, you should talk to your doctor.



If the doctor suspects dementia, you may be referred to a memory clinic or another specialist clinic.



You will be asked about your symptoms and medical history and may have a physical check-up and memory and thinking tests.



You may also have tests like brain scans and blood tests.

Together these tests will help to identify the likely cause of your symptoms.

Brain scans, such as MRI (magnetic resonance imaging) or CT (computerised tomography), can help to rule out other causes of dementia.

To help make a specific diagnosis of DLB, a type of scan called a SPECT scan (or 'DaTscan') may be used. This type of scan can show changes in the brain that are more common in this type of dementia. However, people with very clear-cut symptoms of DLB or PDD may not need these tests.



## Treatments

There are some treatments that can help with the symptoms of DLB and PDD.

There is evidence that the drugs used to treat Alzheimer's disease may help to improve some of the symptoms of DLB and PDD, including problems with thinking skills and hallucinations.

### These drugs are called:

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donepezil

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rivastigmine

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galantamine

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memantine

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A doctor may consider antipsychotic drugs to treat agitation or aggression in dementia. However, people with DLB can have severe side-effects from these drugs so treatment should be carefully monitored. The doctor should first consider an assessment of the person's health and environment. This could help identify any causes or triggers of agitation or aggression that could be addressed without medication.

Movement symptoms in DLB can be treated using physiotherapy or with levodopa, a drug used in Parkinson's disease. There is a risk this drug may cause visual hallucinations or other mental health symptoms to appear or get worse. If this happens, tell your doctor.

Practical steps, such as moving sharp objects away from the bed, can reduce the risk of injury during disturbed sleep. There are also drugs available that can help people who act out dreams.

Non-drug treatments, such as cognitive therapies, exercises and group activities, may also help with some of the symptoms. You can discuss your treatment options with the doctor.

For more detailed information ask for our '**Treatments for dementia**' booklet.



### Risk factors

Age is the biggest known risk factor for the development of DLB. We know that conditions like high blood pressure and high cholesterol are risk factors for other causes of dementia such as Alzheimer's disease. There is some evidence to suggest this may also be true for DLB. If you have concerns, you can speak to your doctor about managing these conditions.

Recent studies have found several genes linked to a higher risk of DLB, including a known risk gene for Alzheimer's. While these discoveries help us to understand the biology of DLB, having one of these risk genes does not mean you will definitely develop the disease. There is no test available on the NHS for these genes.

### Support

Living with DLB can present challenges, but there are organisations that offer help and support. The Lewy Body Society, in partnership with Parkinson's UK, provides support and advice for people with DLB, their families and carers. You can contact a helpline advisor on **0808 800 0303** or by emailing **hello@parkinsons.org.uk** and find information at **www.lewybody.org** and **www.parkinsons.org.uk**

For contact details of other organisations offering support and advice, ask us for our booklet '**Support for people affected by dementia: organisations that can help**' or visit our website at **www.alzheimersresearchuk.org**

You can also speak to your doctor or nurse.



## Send me more information

For free information, simply complete this slip and drop it straight in a post box. Alternatively, phone us on **0300 111 5555**.

### I would like to know more about

Dementia: symptoms, diagnosis, causes and risk reduction (SCIHIAAD)

Treatments for dementia (SCIHITMT)

Support for people affected by dementia: organisations that can help (SCIHCARE)

The latest dementia research (SMTTHINK)

Name

Address

Email

We'd like you to be the first to know about the latest research and how your support makes a difference, as well as ways you can get involved and help fund our life-changing work. We'll keep your information safe and never sell or swap it with anyone.

Let us know how we can contact you (tick below):

Post  Email  Telephone  Text message

You can change how we talk to you at any time, by calling **0300 111 5555** or emailing **enquiries@alzheimersresearchuk.org**

Our Privacy Notice can be found at **www.alzheimersresearchuk.org/privacy-policy** and explains how we will use and store your information.

## Research

Alzheimer's Research UK  
has funded more than

# £17.4 million

of pioneering research to  
help advance our understanding  
of dementia with Lewy bodies.



The research we are funding is looking at the alpha-synuclein protein and other proteins involved in the disease. This is building a clearer picture of why and how these proteins build up and affect the brain. Our scientists are also working to develop new and innovative ways to detect DLB, and identifying targets for the development of new treatments.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs possible.



### Find out more

If you have questions about dementia research or want to find out more about how to get involved in research, contact our **Dementia Research Infoline** on **0300 111 5 111** or email **[infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)**

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages.

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We are the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



### Contact us

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