

What is dementia with Lewy bodies?



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**



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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 aims to give an introduction to DLB. It provides an overview of the causes, symptoms and treatments.

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

The booklet was updated in January 2016 and is due to be reviewed in January 2018. Please contact us if you would like a version with references or in a different format.

Dementia is used to describe a group of symptoms – these include memory loss, confusion, mood changes and difficulty with day-to-day tasks.

What is dementia with Lewy bodies?

There can be a number of different causes of dementia, with Alzheimer's the most common.

Dementia with Lewy bodies (DLB) is the third most common cause of dementia. For every 100 people with dementia, around 15 of them will have dementia caused by DLB. That means roughly 100,000 people in the UK are likely to have DLB.

Some people can show features of both Alzheimer's and DLB.



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Symptoms

Dementia with Lewy bodies can cause common dementia symptoms, including memory loss, spatial awareness problems and a decline in problem solving skills.

There are also some more specific symptoms associated with the disease. Some of these are also seen in Parkinson's dementia.

These symptoms include:



Alertness

Changes in alertness, attention and confusion, which may be unpredictable and change from hour-to-hour or day-to-day.



Movement problems

Parkinson's disease-type symptoms such as slowed movements, muscle stiffness and tremors.



Visual hallucinations

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



Sleep disturbances

Acting out dreams or shouting out while sleeping which can disrupt sleep and potentially cause injury.



Stability

Fainting, unsteadiness and falls.

DLB is a progressive condition which means symptoms get worse over time. As the disease progresses, people will need increasing help with eating, moving, dressing and toileting. DLB can progress slowly over several years but the speed of progression and type of symptoms can vary from person to person.

Diagnosis

It is important to get the right diagnosis so that appropriate treatments and help can be given. If you are worried about your health or someone else's, you should talk to your GP.



If your GP 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 be sent for tests like brain scans and blood tests.

Together these tests will help to identify the likely cause of the memory and thinking problems.



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 may be used to look for changes in the brain which are more common in this type of dementia.

DLB is closely related to Parkinson's disease and people with Parkinson's disease are more likely to go on to develop dementia. If dementia symptoms appear before or at the same time as people start to have movement problems, then a diagnosis of dementia with Lewy bodies is likely to be given. If movement problems are present for a year or more before signs of dementia, then a diagnosis of Parkinson's dementia is likely to be given.

Treatments

There are some treatments that can help with the symptoms of dementia with Lewy bodies.

There is evidence that drugs used to treat Alzheimer's disease, such as cholinesterase inhibitors and memantine, may help to improve some of the symptoms of DLB, including thinking skills and visual hallucinations.

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 and so treatment should be carefully monitored. Instead, a doctor should consider an assessment of someone'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 provoke or worsen visual hallucinations. If this occurs, inform your doctor. Practical steps, such as moving sharp objects away from the bed, can minimise the risk of injury during 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 your doctor.

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

More about the disease

Dementia with Lewy bodies is caused by small round clumps of a protein that build up inside nerve cells in the brain. The protein is called alpha-synuclein and the clumps it forms are called Lewy bodies. The protein clumps damage the way nerve cells work and communicate.

In DLB, the nerve cells that are affected by Lewy bodies are in areas of the brain that control thinking, memory and movement. Lewy bodies are also responsible for the damage that causes movement problems in Parkinson's disease. People with DLB can also show some changes in the brain that are typical of Alzheimer's. This sometimes makes it hard to tell the difference between the two diseases.



Risk factors

Age is the biggest known risk factor for the development of dementia with Lewy bodies. Researchers are working hard to identify other factors that may be involved.

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

Support

Living with DLB can present its challenges, but there are support organisations that can offer you help. 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 '**Caring for someone with 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. You can drop it straight in a post box or put it in an envelope labelled with the freepost address overleaf. Alternatively, phone us on **0300 111 5555**.

I would like to know more about

Dementia: symptoms, diagnosis, causes, prevention and care (SCIHIAAD)

Treatments for dementia (SCIHITFD)

Caring for someone with dementia: organisations that can help (SCIHICARE)

The latest dementia research (SMTTHINK)

Name

Address

We'd really like to keep you updated with the latest research developments, how your support is making a difference, and fundraising activities that you can get involved in. Your details are always held securely, but if you'd rather not hear from us please tick the relevant box:

No information by post No information by phone

If you're happy for us to contact you by email, please enter your email address here:

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Research

Alzheimer's Research UK has funded more than £9.5 million of pioneering research into dementia with Lewy bodies, helping to increase our understanding of the condition.



The research we fund across the UK is looking at the alpha-synuclein protein and other proteins involved in the disease. This will build 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 of detecting DLB, and identifying targets for the development of new treatments.

We believe that dementia can only be defeated through research. Thanks to the generosity of our supporters, we hope to fund many more pioneering studies into dementia with Lewy bodies.



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**

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.

We are the UK's leading research charity aiming to defeat dementia.

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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Dementia Research Infoline

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