

# What is dementia with Lewy bodies?



**Alzheimer's  
Research  
UK**

**The Power  
to Defeat  
Dementia**



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.

## Contents

Introduction	03	Treatments	10
What is dementia with Lewy bodies?	04	Risk factors	12
Symptoms	06	Support	12
Diagnosis	08	Research	15

The information here 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 January 2018 and is due to be reviewed in January 2020. 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, mood changes and difficulty with day-to-day tasks.

There can be 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 of them will have DLB. This means roughly 100,000 people in the UK are likely to have this form of dementia. Some people can show features of both Alzheimer's and DLB; 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. 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.

**Dementia with Lewy bodies is the third most common cause of dementia, affecting around**

**100,000**  
people in the UK


## Symptoms


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





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


### These symptoms include:


 **Alertness**  
Changes in alertness and attention, and periods of confusion, which 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.

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

 **Stability**  
Fainting, unsteadiness and falls.

 **Sense of smell**  
Problems with detecting smells.

DLB is a progressive condition which means symptoms get worse over time. As the disease progresses, people will need more help with eating, moving, dressing and using the toilet.

DLB 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 appropriate 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 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 that 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. 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 provoke or worsen visual hallucinations. If this happens, tell your doctor.

Practical steps, such as moving sharp objects away from the bed, can reduce 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.



### 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 on the NHS.

### 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 and risk reduction (SCIHIAAD)

Treatments for dementia (SCIHITMT)

Caring for someone with 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.



Freepost RTYR-ZUUZ-AULL  
Partridges  
3 Eagle Avenue  
Magnetic Park  
Desborough  
NN14 2WD

## Research

Alzheimer's Research UK has funded more than **£13.4 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 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 will continue to fund 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](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.



# 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

Alzheimer's Research UK  
3 Riverside, Granta Park, Cambridge CB21 6AD



## Supporter care

T: 0300 111 5555  
E: [enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)



## Dementia Research Infoline

T: 0300 111 5 111  
E: [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)

[www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)



This booklet was printed with support from The Perfume Shop who had no input into the content of the booklet.



 **Alzheimer's  
Research  
UK** **The Power  
to Defeat  
Dementia**

Registered charity number 1077089 and SC042474