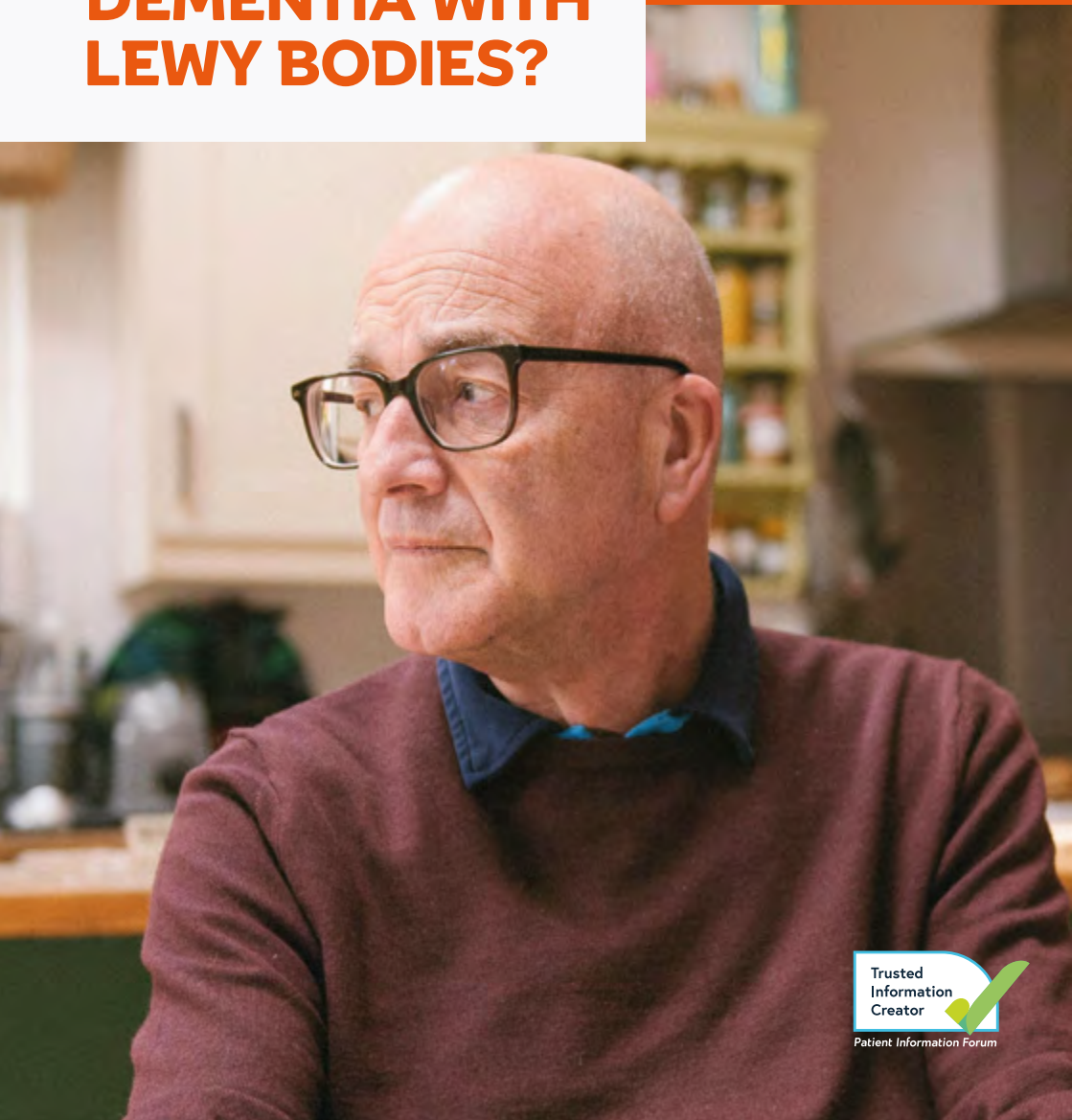


WHAT IS DEMENTIA WITH LEWY BODIES?



INTRODUCTION

This booklet provides information about dementia with Lewy bodies. It's for anyone who wants to know more about the condition, including people affected and their loved ones.

The information here does not replace advice that doctors, pharmacists, or nurses may give you. If you are worried about your health, including memory and thinking problems, speak with your doctor as soon as possible.

The booklet was updated in December 2023 and is due to be reviewed in December 2025, it was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please contact us using the details below if you'd like a version with references or in a different format.

ANY QUESTIONS

If you have questions about dementia or dementia research, or any feedback on this booklet, you can contact the Dementia Research Infoline on **0300 111 5111** or email infoline@alzheimersresearchuk.org or write to us using the address on the back page.

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WHAT IS DEMENTIA WITH LEWY BODIES?

The word dementia is used to describe a group of symptoms. These include memory loss, confusion and changes to communication, mood and behaviour.

These symptoms affect day-to-day life. Dementia is caused by different diseases. Dementia with Lewy bodies is the third most common disease that causes dementia after Alzheimer's disease and vascular dementia. For every 100 people who have dementia, about 10-15 will have dementia with Lewy bodies. This means that around 100,000 people in the UK have this type of dementia.

Some people can have mixed dementia, where they are affected by two different diseases at the same time. Someone may be diagnosed as having dementia with Lewy bodies and Alzheimer's disease, or dementia with Lewy bodies and vascular dementia. This means they will be affected by symptoms of both types of dementia.



Dementia with Lewy bodies is often abbreviated to DLB. In DLB, small round clumps of protein 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.

As DLB progresses, Lewy bodies build up and this accumulation is accompanied by damage to nerve cells. This damage affects the way that our brain cells communicate. In DLB, the nerve cells that are affected are in areas of the brain that control our thinking, memory, and body movement.

DLB, PARKINSON'S DISEASE AND PARKINSON'S DISEASE DEMENTIA

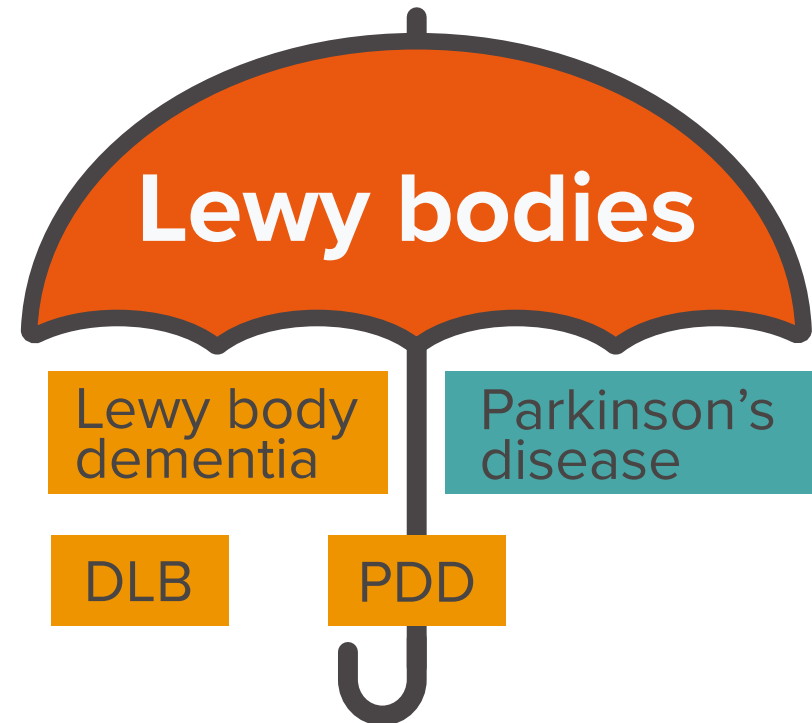
Dementia with Lewy bodies is closely related to Parkinson's disease (PD). The build-up of Lewy bodies is also found in Parkinson's and leads to symptoms like movement problems and tremors.

People who have Parkinson's disease are more likely to go on to develop dementia. This is known as Parkinson's disease dementia (PDD).

Dementia with Lewy bodies and Parkinson's disease dementia can affect people in very similar ways, and people will receive a diagnosis of one or the other dependent on the timing of certain symptoms.

- If memory problems and dementia symptoms appear before or at the same time as movement problems and symptoms, then a diagnosis of DLB is likely to be given.
- If Parkinson's movement problems are experienced for a year or more before memory and thinking symptoms appear, a diagnosis of PDD is likely to be given.

It is not always easy to tell if a person has DLB or PDD, as the timing of the start of memory and thinking symptoms is not always clear. Lewy Body Dementia is a term that describes both DLB and PDD and can be useful in these situations. It can also be useful to group these conditions as there are many similarities, both in symptoms and in the needs of people with the conditions and their families.



SYMPTOMS

Dementia with Lewy bodies can cause common dementia symptoms like memory loss and confusion, as well as other symptoms like changes to alertness.

Everyone's experience of dementia symptoms can be different, but most people have changes to their thinking, memory and behaviour that get worse over time.

Symptoms of DLB can include:

- **Changes in alertness and attention**, and periods of confusion. These periods can be unpredictable and change from hour-to-hour, or day-to-day.
- **Movement problems** such as slower movements, stiffness in the arms and legs, and shaking or trembling. These symptoms are also common in Parkinson's disease.
- **Stability** – people can become unsteady when moving around and be at risk of falling over.
- **Visual hallucinations** – people with DLB may see things that are not really there, for example people or animals. These hallucinations can happen repeatedly and are very realistic for the person experiencing them.
- **Changes to thinking and memory** – people often notice difficulty making plans, and lose the ability to find their way around. Memory can be affected, but this may occur later and be less severe compared to other types of dementia.

- **Mood** – depression and anxiety are commonly seen in DLB but can often be eased with treatment.
- **Sleep problems** – vivid dreams and shouting out or moving while asleep. This can disrupt sleep and may cause injury. Poor sleep quality and more daytime sleeping are more common in DLB than other types of dementia.
- **Sense of smell** – changes to sense of smell or taste.

Dementia with Lewy bodies and Parkinson's disease are progressive diseases. This means that symptoms get worse over time. As the diseases progress, people will need more help with everyday activities like eating, moving, dressing, and using the toilet.

The type of symptoms and the speed at which they change can vary from person to person as DLB or PD progresses. Some research suggests that cognitive decline in people with DLB is more rapid than cognitive decline in those with Alzheimer's disease or PD.

**FOR MORE INFORMATION ABOUT
PARKINSON'S DISEASE YOU CAN GET
IN TOUCH WITH PARKINSON'S UK
[PARKINSONS.ORG.UK](https://www.parkinsons.org.uk) OR 0808 800 0303.**

DIAGNOSIS

If you are worried about symptoms of dementia, your health, or someone else's, you should talk to your GP. There are many causes of memory and thinking problems that are not types of dementia and can be easily treated.

For example, some vitamin deficiencies such as B12 deficiency and some thyroid disorders can cause dementia-like symptoms that can be reversed if detected and treated early. It is important to get the right diagnosis so that the right treatments and help can be given.

When you go to the doctor they will:

- ask you about your symptoms and how they are affecting you.
- check your medical history and general health.
- do some physical tests like blood pressure and a balance or reflexes test.
- ask you to do some memory and thinking tests.
- run blood and urine tests to rule out other causes of your symptoms.

Together these tests will help to identify the likely cause of your symptoms. If the doctor suspects you have dementia, you may be referred to a memory clinic or another specialist clinic where more in depth tests can be done.

If possible, it is helpful if you can bring someone who knows you well to the appointment. This will help the specialist by giving information about any changes they may have noticed.

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

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, when symptoms of DLB or PD are quite clear, someone may not need this test.

For more information about diagnosing memory problems ask us for **'Getting a dementia diagnosis'**. Contact and order details can be found on the back of this booklet.

B12 DEFICIENCY AND SOME THYROID DISORDERS CAN CAUSE DEMENTIA-LIKE SYMPTOMS THAT CAN BE REVERSED IF DETECTED AND TREATED EARLY.

TREATMENTS

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

The drugs used to treat Alzheimer's disease may help to improve some of the symptoms of DLB, including problems with thinking skills and visual hallucinations.

These drugs are called:

- donepezil
- rivastigmine
- galantamine
- memantine.

These drugs boost chemicals that help brain cells to communicate with each other, alleviating some of the memory and thinking symptoms in DLB. Unfortunately they do not work for everyone, and as symptoms become more severe, they may not work as well.

THERE ARE NO MEDICATIONS TO SLOW DOWN THE PROGRESSION OF DLB BUT RESEARCHERS ARE MAKING PROGRESS TOWARDS FINDING LIFECHANGING TREATMENTS.

Agitation and aggression can be common symptoms in dementia. For people who experience these symptoms a doctor should first assess the person's health and environment. This could help to identify any causes or triggers of agitation or aggression, so these can be addressed first before trying medication. A doctor may prescribe drugs called antipsychotics to treat these symptoms. However, people with DLB should be carefully monitored if they are prescribed these drugs as they can cause serious side-effects.

People who experience problems with movement in DLB can be treated using physiotherapy or with levodopa, a drug used for Parkinson's disease. There is a risk that this drug may cause visual hallucinations or confusion symptoms to occur, or to get worse in people who already experience these. Any side effects from medications should be reported to your GP.



For people whose movement symptoms affect them whilst they're asleep, practical steps, such as moving objects away from the bed, can reduce the risk of injury. There is also a medication called clonazepam available to help people with DLB who have disrupted sleep because of movement. For general tips around sleep quality your doctor will be able to give you more advice.

Non-drug treatments, such as cognitive therapy, exercise and group activities may also help with some of the symptoms in DLB. These types of complementary therapies can also help to reduce the isolation and anxiety that some people living with dementia experience.

Other therapies include aromatherapy, animal assisted therapy, music and dance therapy, massage, and reminiscence therapy. These kinds of therapies and activities might not appeal to everyone, and more research is needed to establish their benefits but finding an activity that a person with dementia enjoys can help to enhance general wellbeing.

You can discuss your treatment options with your doctor. For more information ask for our **'Treatments for dementia'** booklet. You can find contact and order details on the back page of this booklet.

Summary of treatments for dementia with lewy bodies:



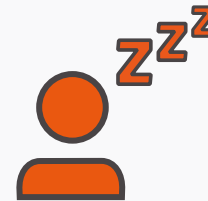
Medications used for Alzheimer's disease that help with some symptoms of DLB



Physiotherapy to manage movement problems and symptoms



Complementary therapies to promote wellbeing such as music therapy and aromatherapy



Medication called clonazepam for people with sleep disruption due to movement



Medication like antidepressants for anxiety, agitation and aggression



Cognitive therapy or speech therapy

RISK FACTORS

A risk factor is something that increases your likelihood of developing a disease or condition.

As with many other types of dementia, there are many risk factors for dementia with Lewy bodies that interact together to cause the disease. Age is the biggest risk factor for the development of DLB, this means that the older we are the more likely it becomes.

We know that conditions like high blood pressure, high cholesterol and diabetes are risk factors for other types of dementia like Alzheimer's disease and there is evidence to suggest they are risk factors for the development of DLB too.

MEN ARE MORE LIKELY TO GET DLB THAN WOMEN AND PEOPLE WITH A FAMILY HISTORY OF PARKINSON'S DISEASE OR DLB HAVE A HIGHER RISK TOO.



For good brain and heart health, and to help lower your risk of dementia with Lewy bodies:



If you have diabetes, ensure your condition is managed well



Keep physically and socially active



Don't smoke



Maintain a healthy weight



Eat a healthy balanced diet



Only drink alcohol in line with government recommendations



Keep high cholesterol and blood pressure under control



Keep your brain active by doing things you enjoy and spending time with others



Have your hearing checked regularly

While there's no guaranteed way to completely prevent dementia with Lewy bodies, evidence suggests that looking after our brain health may reduce our risk of dementia.

If you have concerns about your dementia risk or any of the risk factors mentioned here, you can speak to your GP about managing them.

Some research 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 more about the disease, there is no test available on the NHS for risk genes associated with DLB or Alzheimer's because carrying one of these genes does not mean that you will definitely develop the condition.

For more information on dementia risk factors, see our booklet '**Reducing your risk of dementia**' and for more about genetics and dementia, our booklet '**Genes and dementia**' contains further information. Contact and order details can be found on the back of this booklet.

CARRYING A RISK GENE DOES NOT MEAN YOU WILL GO ON TO DEVELOP THE CONDITION DUE TO OTHER CONTRIBUTING RISK FACTORS LIKE AGE AND LIFESTYLE.

SUPPORT

Living with DLB or another type of dementia can present challenges, but there are organisations that offer help and support. If your partner or loved one has DLB, it can be challenging.

It is important to make time in the week to do things for yourself, and spend time with friends, as well as your partner or loved one.

The **Lewy Body Society** provide support and advice for people with DLB, their families and carers. You can find information at lewybody.org

Helpline support, offering practical tips and medical advice is provided by **Admiral Nurses** on **0800 888 6678** or helpline@dementiauk.org

Parkinson's UK also provide information and support about DLB and PDD. Visit parkinsons.org.uk/information-and-support/thinking-and-memory-changes or contact them on **0808 800 0303** or hello@parkinsons.org.uk

alzheimersresearchuk.org

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**'. Contact and order details can be found on the back of this booklet.

You can also speak to your doctor or nurse about local support services for people with dementia.



TAKING PART IN RESEARCH

Through research we'll bring about breakthroughs that will change lives, but scientists need your help.

People with dementia, their carers, and people without dementia are all needed to take part in vital research studies. If you're interested in taking part, you can register at joindementiaresearch.nihr.ac.uk or by calling **0300 111 5111**.



SHARE YOUR STORIES

If you have been diagnosed with dementia with Lewy bodies and would like to share your story to inspire others, or to help shape our work please get in touch via stories@alzheimersresearchuk.org

RESEARCH

Alzheimer's Research UK has funded more than **£7.5 million** of pioneering research into dementia with Lewy bodies. We've funded a further **£25.3 million** of research into finding new ways to detect and diagnose dementia.

Some examples of DLB research that we have funded includes a study comparing sleep patterns of people with and without dementia with Lewy bodies. This project is being carried out by researchers at Northumbria University and aims to trial and improve a sleep measuring technique. Researchers from University College London are using advanced MRI scans to understand the changes within the brain that occur in people with DLB and visual hallucinations.

With your support, we will fund many more studies into dementia with Lewy bodies. We promise we will not stop until dementia can no longer destroy lives.

**We are Alzheimer's Research UK.
We exist for a cure.**

Alzheimer's Research UK is the UK's leading dementia research charity. We provide free dementia health information, like this booklet and others.

If you would like to view, download or order any of our other booklets please use the details below. If you'd like to help us review and improve our booklets, visit alzres.uk/reviewer

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