



Alzheimer's
Research
UK

What is dementia with Lewy bodies?



Patient Information Forum

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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. We hope this background information is helpful.

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 2021 and is due to be reviewed in December 2023. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please get in touch using the contact details below if you'd like a version with references or in a different format.

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

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.

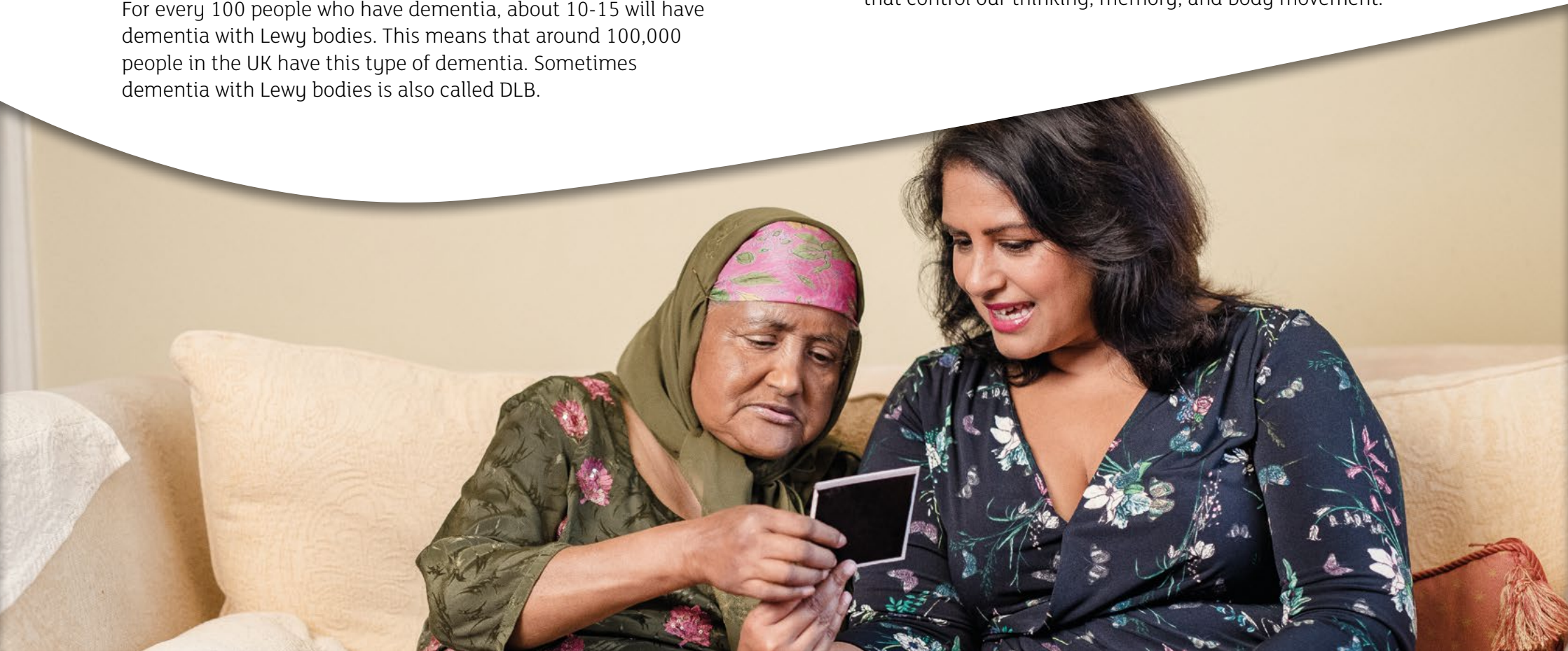
These symptoms affect day-to-day life. Dementia is caused by different diseases, dementia with Lewy bodies is the third most common disease that causes dementia.

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. Sometimes dementia with Lewy bodies is also called DLB.

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.

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 this damage affects the way that they 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, but they are different conditions. 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. 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.

For more information about Parkinson's disease you can get in touch with **Parkinson's UK** www.parkinsons.org.uk or **0808 800 0303**.



It is not always easy to tell if a person has DLB or PDD, as the timing of the onset of memory and thinking problems is not always clear.

Lewy body dementia is an umbrella term that includes 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.

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.

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 doctor 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, having one of these risk genes does not mean you will definitely go on to develop it.

To keep our brains healthy:



Don't smoke



Have your blood pressure, cholesterol and hearing checked regularly



Keep blood glucose in check if you have type 2 diabetes



Drink alcohol in line with government recommendations



Maintain a healthy weight



Stay connected and do hobbies you enjoy



Eat a healthy balanced diet



Keep physically and mentally active

There is no test available on the NHS for risk genes associated with DLB or Alzheimer's. This is because 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.

For more information on genetics and dementia, ask for our booklet '**Genes and dementia**'. Contact and order details can be found on the back of this booklet.



Symptoms

Dementia with Lewy bodies can cause both 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 start to get worse over time.

Dementia with Lewy bodies and Parkinson's disease dementia 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.

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

Symptoms of DLB can include:



Changes in alertness, attention, and periods of confusion. These periods can be unpredictable and change from hour-to-hour, or day-to-day.



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 realistic.



Mood and emotions. Depression and anxiety are commonly seen in DLB, but can often be alleviated with treatment.



Sleep problems. Vivid dreams and shouting out or moving while asleep. This can disrupt sleep, and may cause injury.



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.



Changes to thinking and memory. People often notice difficulty planning activities, and loss of ability to find their way around. Memory can be affected, but this may occur later and is often less affected.



Stability, people can become unsteady when moving around and be at risk of falling over.



Changes to sense of smell or taste.

Diagnosis

If you are worried about symptoms of dementia, your health, or someone else's, you should talk to your doctor. There are many causes of memory and thinking problems, including vitamin deficiencies and thyroid disorders.

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.



A memory clinic or specialist can perform:

- 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 PDD are quite clear, someone may not need this test.

For more information about diagnosing dementia ask us for '**Problems with your memory?**'. Contact and order details can be found on the back of this booklet.

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 currently no medications available to slow down the progression of DLB, but researchers are making progress towards finding life-changing 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 antipsychotics to treat these symptoms. However, people with DLB should be carefully monitored if they are prescribed these drugs as they can experience serious side-effects.





People who experience movement symptoms 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 happen, or to get worse in people who already experience these. Any side effects from medications should be reported to your doctor.

For people who experience movement during sleep, moving objects away from the bed can reduce the risk of injury. There are also medications available to help people with DLB who have disrupted sleep because of movement.

Non-drug treatments, such as cognitive therapy, exercise and group activities may also help with some of the symptoms in DLB. 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.

Support

Living with DLB or another type of dementia can present challenges, but there are organisations that offer help and support.

The **Lewy Body Society** provide support and advice for people with DLB, their families and carers. You find information at **www.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 **www.parkinsons.org.uk** or contact them on **0808 800 0303** or **hello@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**'. 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.

How to get involved

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 dementia research studies.

If you're interested in taking part in research you can register to see which studies you can take part in via **Join Dementia Research** at www.joindementiaresearch.nihr.ac.uk or scan the QR code



Research

Alzheimer's Research UK has funded more than **£6.5 million** of pioneering research into dementia with Lewy bodies. We've funded a further **£21 million** of research into finding new ways to detect and diagnose dementia. Accurate and early diagnosis is crucial to delivering effective treatments to people affected.

Researchers from **Northumbria University** are using a non-invasive technique to compare sleep patterns of people with and without dementia with Lewy bodies. This project 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.

Projects like these enable us to understand more about dementia, and to develop new diagnosis methods and treatments.

You can find out more about this project and our other funded research by visiting www.alzheimersresearchuk.org/research/research-projects

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

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 details below.

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