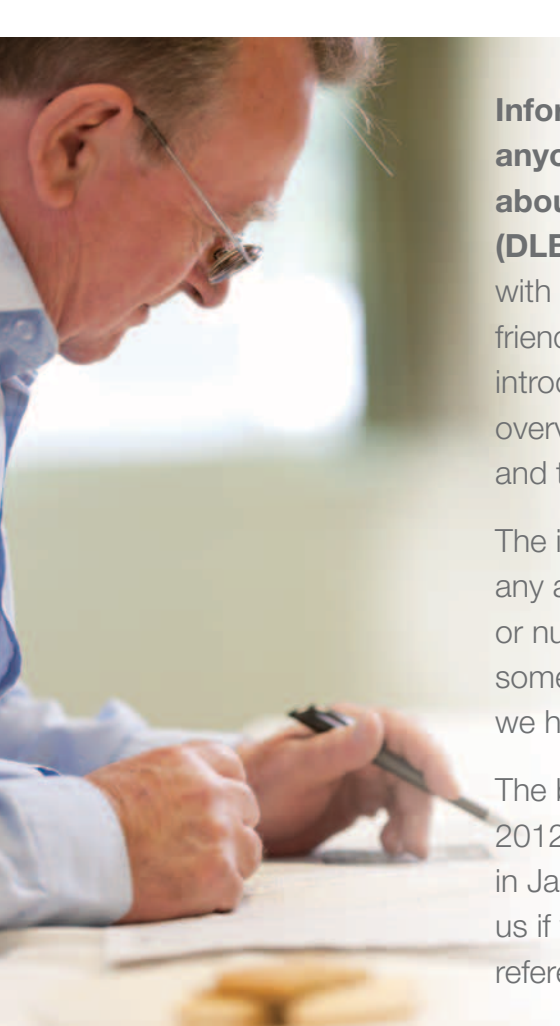




# What is dementia with Lewy bodies?



**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, by providing 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 written in January 2012 and is due to be updated in January 2014. Please contact us if you would like a version with references or in a different format.

## Contents

03 What is dementia with Lewy bodies?

---

04 Symptoms

---

05 Diagnosis

---

06 Treatments

---

07 Support

---

08 Causes

---

08 Risk factors

---

11 Research

---

## What is dementia with Lewy bodies?

**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 the most common.

Dementia with Lewy bodies (DLB) is the third most common cause of dementia. It affects about 15% of people with dementia, over 100,000 people in the UK. Some people can show features of both Alzheimer's and DLB, sometimes called mixed dementia.

DLB may also be called Lewy body disease, diffuse Lewy body disease, Lewy body variant of Alzheimer's disease, cortical Lewy body disease and senile dementia of Lewy body type.

Dementia with Lewy bodies (DLB) is the **third most common cause of dementia.**



## 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 symptoms are also seen in Parkinson's dementia.

### These symptoms include:

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

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

Visual hallucinations. These can involve seeing people or animals that aren't really there.

Sleep disturbances which can cause people to move or talk in their sleep.

Fainting, unsteadiness and falls.

DLB is a progressive condition which means symptoms get worse over time. DLB can progress slowly over several years but the speed of progression and type of symptoms can vary from person to person.

## Diagnosis

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.

If your GP suspects dementia, they may refer you 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 a memory test. They may also send you 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 DaT scan may be used to look for changes in the brain which are more common in this type of dementia.

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.





## Treatments

There are some treatments which can help with the symptoms of dementia with Lewy bodies (DLB). There is evidence that cholinesterase inhibitors used to treat Alzheimer's disease may help to improve some of the symptoms of DLB, including visual hallucinations. Antipsychotic drugs may be used 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.

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

For more detailed information ask for our 'Treatments for dementia' booklet using the contact details on the back of this booklet.



## Support

Living with DLB can present its challenges, but there are support organisations who 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 'All about dementia' or visit our website at **www.alzheimersresearchuk.org**  
You can also speak to your doctor or nurse.



## Causes

**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 spheres it forms are called Lewy bodies after Dr Frederick Lewy who first observed them. The protein clumps damage the way nerve cells work and communicate. The nerve cells that are affected by Lewy bodies are in areas of the brain that control thinking, memory and movement. People with DLB can also show some changes in the brain which are typical of Alzheimer's – sometimes making it difficult to discriminate between the two conditions.

## Risk factors

**Although age seems to be the biggest known risk factor for the development of dementia with Lewy bodies, more work is needed to identify other factors which may be involved.**

Research is underway to learn more about whether there is a genetic basis.



## 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 01223 843899.

### I would like to know more about

Dementia; symptoms, diagnosis, causes, prevention and care ☐

Treatments for dementia ☐

The latest dementia research ☐

Title \_\_\_\_\_

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We would like to keep you informed about our research and our progress in defeating dementia. However, if you do not wish to receive any further communications from us, please tick here: ☐

**FREEPOST RRBV-CKHR-YBRA**  
Alzheimer's Research UK  
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Cambridge  
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## Research

Over the last decade Alzheimer's Research UK has funded more than £3 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 known to clump together to form Lewy bodies. This will build a clearer picture of why and how these proteins build up and damage normal brain function.

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.

# Have your say

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.

## About us

Alzheimer's Research UK is the UK's leading dementia research charity funding world-class research to find ways to prevent, treat or cure dementia. Help us defeat dementia by donating today

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

## Contact us

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