

LBD is the second most common form of age-related neurodegenerative disease

To find out more please visit our website at [lewybody.org](http://lewybody.org)

### Join the Society

Established in June 2006, The Lewy Body Society was the first organisation in Europe to be dedicated exclusively to Lewy body dementia. The Society's mission is to sponsor research into LBD and to raise awareness and educate the general public, the medical and caring professions and people in decision-making positions about all aspects of the disease.

Calls for grant applications for researchers are posted on the website.

Please help in our work by joining the Society. There is no fee and you can be as active, or not, as you wish.

Name: .....

Address: .....

Postcode: .....

Email: .....

Telephone: .....

I would like to make a donation of £ ..... to the Lewy Body Society and I am a UK taxpayer. Please treat as Gift Aid.

We will only use your personal details to keep you informed about our work. You can opt out at any time and we won't pass your details on to anyone else.



## The Lewy Body Society

A: Unity House, Westwood Park, Wigan WN3 4HE  
T: 01942 914000 E: [info@lewybody.org](mailto:info@lewybody.org)  
[www.lewybody.org](http://www.lewybody.org)

 [lewybodysociety](https://www.facebook.com/lewybodysociety)  [lbsorg](https://twitter.com/lbsorg)

**amrc** Member of the Association of Medical Research Charities

**Dementia UK helpline: 0800 888 6678**  
Calls answered by Dementia UK Admiral Nurses  
Monday to Friday 9am-9pm  
Saturday and Sunday 9am-5pm

The information in this brochure should not be considered medical or professional advice. It is a general overview only. The Society is not responsible for any errors or omissions herein, or any action resulting therefrom. If you think that you or someone you know might be experiencing symptoms of Lewy body dementia, please consult your GP or another qualified medical professional immediately.

Shining a light on Lewy body dementia



## The Lewy Body Society

A registered charity in England & Wales (1114579) and Scotland (SC047044)  
© The Lewy Body Society 2018

LBD  
accounts for  
15-20% of all  
cases of  
dementia



### A message from the patron of the Lewy Body Society, Miss June Brown MBE

“

I've become patron of the Lewy Body Society because my husband, Robert Arnold, died of Lewy body dementia. The charity was founded so that more people become aware of this disease and how different it is from Alzheimer's and indeed, Parkinson's diseases, as Lewy Body sufferers often show the same symptoms.

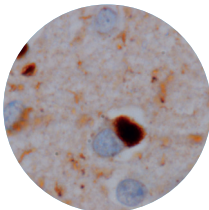
It is extremely important that the cause of dementia is correctly diagnosed as different diseases require different treatment. The wrong drugs can be potentially very dangerous.

I think the Lewy Body Society is so important because it is the only organisation in all of Europe dedicated solely to this disease, providing information and sponsoring research. It is imperative that more research is done in the hope of prevention, better treatment, and ultimately, a cure.

”

### What's it 'L' about?

Lewy body dementia (LBD) is the second most frequent cause of age-related neurodegenerative dementia. It is thought that around 130,000 people in the UK are living with this common, but little known disease.



Lewy bodies are microscopic protein deposits in the brain associated with the death of cells. They are named after Dr Freidrich Heinrich Lewy (1885-1950) who discovered these deposits in 1912.

The term "*Lewy body dementia*" includes the dementia associated with Parkinson's disease. The symptoms are the same but the Lewy bodies are found in different areas of the brain. The diagnosis an individual receives will depend on the order in which symptoms first appear.

### Symptoms

Each case of LBD is as individual as the person who lives with it. The main symptom of LBD is **dementia**: progressive decline in mental abilities serious enough to interfere with normal daily activities. As this definition applies to all forms of dementia, LBD can easily be mistaken for Alzheimer's disease. As Alzheimer's disease affects 60% of all people living with dementia, it is the most widely recognised but by no means the only form of age-related dementia.

The primary cognitive symptom of LBD is often **loss of executive function** such as spatial awareness and problem-solving ability. With Alzheimer's it is usually memory loss. People living with LBD frequently experience **extreme swings of consciousness**, from alert to confused, from lucid to muddled. If a person who has been diagnosed with Alzheimer's disease exhibits dramatic fluctuations, it could be LBD.

Two-thirds of people diagnosed with LBD experience vivid and recurrent visual **hallucinations**, something which is rare in early Alzheimer's.

**Parkinson's-like symptoms** are often present in LBD. This means motor difficulties such as slow movement, freezing, falls, and sometimes the tremor characteristic of Parkinson's. With both LBD and Parkinson's the person may experience other symptoms such as sudden drop in blood pressure, difficulty in swallowing, incontinence or constipation.

If someone recently diagnosed with Parkinson's also experiences the mental symptoms described above it could be LBD.

Other important symptoms are sleep disturbances, such as acting out dreams, and severe sensitivity to neuroleptic drugs. **Anti-psychotic drugs should only be prescribed by someone experienced in the illness as many of these drugs can be extremely harmful or even fatal to people with LBD.**

### Diagnosis

Because of its similarities to Alzheimer's and Parkinson's, LBD is often misdiagnosed. At present a diagnosis of LBD can only be confirmed by autopsy but careful clinical evaluation of the patient and their symptoms can in many cases form the basis of a reasonably confident diagnosis. Early and accurate diagnosis is essential for managing this condition.

### Treatment

Treatment consists of managing symptoms by both pharmaceutical and non-pharmaceutical intervention. Responses vary between individuals. Pharmaceutical treatment, if effective, cannot cure LBD, but may slow down its progression. Unfortunately a cure has not yet been discovered.