

Established in June 2006, The Lewy Body Society is the only charity in Europe exclusively concerned with dementia with Lewy bodies. The charity's mission is to support research into DLB and to raise awareness for the general public and educate those in the medical profession and decision making positions about all aspects of the disease.

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 have DLB
- ☐ I think I may have DLB
- ☐ I am caring for someone with DLB
- ☐ I know someone with DLB
- ☐ I am interested in learning more about drug trials
- ☐ I am just interested in DLB
- ☐ I would be willing to organise a meeting to learn more about DLB

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

You can also show your support for the Lewy Body Society by buying and displaying its distinctive wristbands and totebags.

Spotty wristbands are £2.50 each (postage included).



The lightweight but strong totebags are a generous 44cm x 39cm x 13cm and cost £4.00 (postage included).



Cheques payable to; The Lewy Body Society, to be sent to Hudson House, 8 Albany St, Edinburgh EH1 3QB. Cash at your own risk.

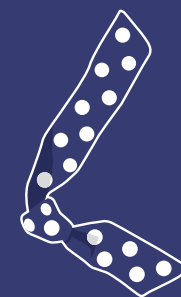
The information in this leaflet is an overview only and is not meant, or to be taken, as medical advice. It has been scrutinised and checked for accuracy by the Lewy Body Society's Medical and Scientific Advisory Panel but is not intended to be professional advice. If you think you or someone you know may have DLB, a doctor must be consulted.

For more information:

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

# The Lewy Body Society

*The more people who know,  
the fewer people who suffer.*



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Registered charity number 111579

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.*

*June Brown*

## What's it 'L' about?

Dementia with Lewy bodies, also known as Lewy body disease, is the second most frequent cause of age-related neurodegenerative dementia.

Approximately 130,000 people in the UK are thought to suffer from this little known but not uncommon, devastating disease.



Lewy bodies are microscopic protein deposits in the brain associated with the death of cells.

They are named after Dr Friedrich Heinrich Lewy (1885-1950), a German-born neurologist who was a colleague of Dr Alzheimer's.

## Symptoms

Each case of dementia with Lewy bodies (DLB) is as individual as the person who suffers from it. The main symptom of DLB is dementia, or progressive decline in memory and thinking serious enough to interfere with normal daily activities. This can easily be mistaken for Alzheimer's disease (AD) or for Parkinson's disease with dementia (PDD).

Unlike people with AD, DLB patients 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 can sometimes have a normal conversation and at other times is unable to understand anything at all, it could be DLB.

Two-thirds of patients with DLB experience vivid and recurrent visual hallucinations, something which is not as common in early AD.

Spontaneous Parkinsonism is common in people with DLB. This means motor difficulties such as slow movement, rigidity and falls and sometimes the tremor characteristic of PD. In both DLB and PD the patient may suffer from autonomic symptoms such as sudden drop in blood pressure upon standing, difficulty in swallowing, incontinence or constipation. If someone recently diagnosed with PD is suffering from the mental symptoms listed, it could be DLB.

Other important symptoms can be disturbances in REM sleep 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 DLB.

## Diagnosis

A diagnosis of DLB is less likely if the person has had a stroke or other illness which may have affected motor or mental ability.

At present a diagnosis of DLB can only be confirmed by autopsy but a careful clinical evaluation of the patient and his or her symptoms can in many cases form the basis for making a reasonably confident lifetime diagnosis.

## Treatment

Diagnostic criteria and guidelines for treatment of dementia with Lewy bodies have been agreed and published. Treatment consists of managing symptoms by both pharmaceutical and non-pharmaceutical intervention. There is no universal response to either the drugs or non-medical therapies. Reactions are as diverse as each person involved.