

HOW CAN I KNOW FOR SURE IT IS LEWY BODY DEMENTIA?

There is no simple test to prove someone has LBD, but experts look for the core symptoms (sleep problems, fluctuating cognition, slow and small movements, visual hallucinations and sensitivity to neuroleptic drugs). Your GP may talk with you about the changes you, or those around you have noticed and do a simple test to check your memory and thinking. The doctor should also give you a physical examination, review what medicines you are taking and test your blood, in order to rule out other problems that could affect your thinking or memory. Fluctuating states of consciousness can make diagnosing LBD difficult because your symptoms may not be present during the doctor's appointment. Keeping a log of when symptoms appear can be a useful tool for diagnosis. If your GP thinks the problem is dementia, you may be referred to a memory clinic for an assessment. The specialists there can discuss your concerns with you and organise further tests, including brain scans, to determine whether you have dementia and if so, which kind.

"The fluctuating nature of dementia with Lewy bodies has given us the bonus of knowing that in the positive 'ups', we can do special things together, like having a trip out. We plan for the times when my husband will cope well, and as soon as he shows the signs of improvement, we put the 'high day' plan into action!"

Wife of someone with LBD

People with Parkinson's disease are at risk of developing dementia (Parkinson's disease dementia or PDD) which differs from LBD only in the order of onset of symptoms. Mental symptoms precede physical ones in LBD, with PDD it is the opposite. If you have Parkinson's disease and are worried about the symptoms listed in this leaflet, talk with your Parkinson's Nurse or Neurologist.

TREATMENT

Although a cure for dementia has not yet been found, there are some drugs and treatments which can help manage symptoms. Be sure to ask the doctor about possible side effects of any drugs suggested. Some drugs which improve movement can worsen problems with thinking and vice versa. And some drugs, called neuroleptics, which may be prescribed for hallucinations, sleep problems and mood control, can have extremely serious and negative side effects for some people with LBD.

Keeping active and involved with hobbies and other people is very important – you can find out more from our leaflet on 'Living Well with a Lewy Body Dementia'.

www.lewybody.org



Founded in 2006, the Lewy Body Society is the only organisation in Europe dedicated exclusively to LBD. The charity's mission is two-fold: (1) to raise awareness of the disease amongst the general public and educate medical professionals and decision-makers and (2) to support research into the disease.

A WORD FROM OUR PATRON

"I became 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: the more people who know, the fewer people who suffer."

June Brown MBE

SOME USEFUL SOURCES OF SUPPORT

The Lewy Body Society

Hudson House, 8 Albany Street Edinburgh EH1 3QB
Tel: 0131 473 2385
Email: info@lewybody.org
Registered Charity Number 1114579

Admiral Nursing DIRECT

A national helpline and email service provided by experienced Admiral Nurses who give practical advice and emotional support to anyone affected by dementia. Call **0845 257 9406** or email direct@dementiauk.org

Carers UK

Provide information and advice about caring alongside practical and emotional support for carers.
Phone: 0808 808 7777 Email: advice@carersuk.org

For more resources, help, information and support please visit the Lewy Body Society website www.lewybody.org

You can also find us on Facebook



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THE LEWY BODY SOCIETY

The more people who know, the fewer people who suffer

Lewy body dementia Are you worried about Dementia?

If you have picked up this leaflet, you may be worried that you or someone you care about has dementia. We will cover what dementia is and look at one group called Lewy (sounds like 'loo-ee') body dementia



WHAT IS DEMENTIA?

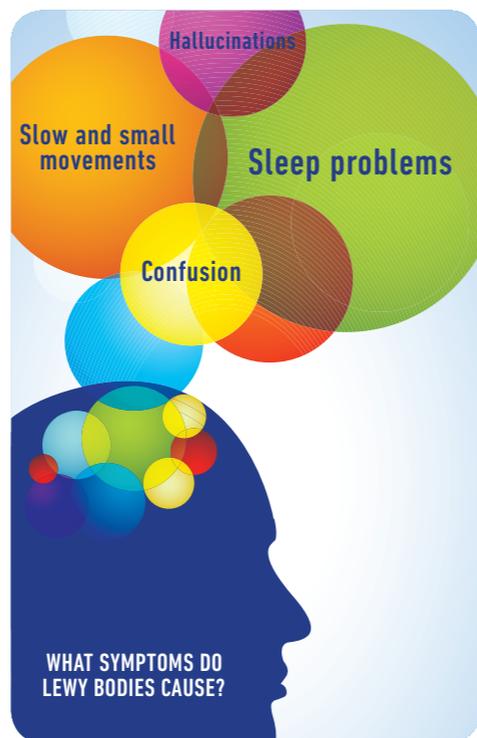
Dementia is defined as an abnormality of the brain which affects thinking ability and interferes with a person's activities of daily living (ADLs). It is not a normal part of ageing and indicates a problem more serious than occasional forgetfulness.

Seeing, moving, planning for the future and keeping calm are directed by different areas in the brain. Someone with dementia may have problems with these things. They might become confused, anxious or cross in everyday situations and there may be changes in:

- **Thinking speed** (slower)
- **Comprehension** (struggle to deal with information or grasp a story, may not know familiar places or objects)
- **Planning** (does things in the wrong order)
- **Judgement** (difficulty making decisions and choices; delusions – thoughts that don't match reality – such as irrational fearfulness or feeling under attack)
- **Language** (problems finding or using words)
- **Emotions** (emotions sometimes out of control, may feel low or not care about things)
- **Memory** (forgetful or slow to remember).

When many people think of dementia they think of Alzheimer's disease, which is the most common, but not the only, form of dementia and which starts with significant memory loss. It accounts for about 60% of all people with dementia. Lewy Body Dementia (LBD) is the second most common type of dementia. Vascular dementia is another common type. It is possible for more than one type of dementia to be present at the same time. This is known as mixed dementia.

Dementia: "It isn't always memory and it isn't just memory".



www.lewybody.org

WHY FIND OUT IF IT IS DEMENTIA?

It is possible to live well with dementia and many people do. There are important reasons for finding out if your problems are caused by dementia.

- 1 It might be something else. An infection, a reaction to medicine or the lack of certain vitamins can affect your behaviour and thinking. These problems can be treated or cured.
- 2 Although there is currently no cure for dementia, some treatments can help with the symptoms and slow down the progress of the disease. The earlier the treatment is started, the longer you can stay well.
- 3 An early diagnosis of dementia means that you have more time to enjoy life and make plans for the future whilst you are as well as possible. There are many organisations and agencies who can help you sort out your affairs, such as finances and property, to make sure your wishes are known and carried out. (See contact details at the end of this leaflet.)
- 4 You are more likely to find out about new types of treatment and support. More research into dementia is now being funded than ever before. You may be able to participate in a clinical trial.
- 5 Knowing what is the matter with you can be a relief. A diagnosis explains why you have been thinking, feeling or acting differently. A diagnosis can direct you to available support and services. Whether a helpline, a support group or an online network, there are many people out there to help you face the challenge of a future with dementia.

WHY DOES IT MATTER WHAT SORT OF DEMENTIA IT IS?

Knowing the kind of dementia you have helps you and your loved ones make sense of symptoms and feel more in control. It can also help your medical professionals make informed decisions about what treatments are appropriate for you.

WHAT IS LEWY BODY DEMENTIA?

LBD is the name that doctors apply to both Dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). They have the same symptoms but different names depending on the order

the symptoms appear. If the mental problems appear before or at the same time as movement problems, such as a shuffling walk, the diagnosis will be 'dementia with Lewy bodies'.

Lewy bodies are abnormal formations in the brain of the protein, alpha-synuclein. They are named after Dr Frederick Lewy, who discovered these clumps. Lewy bodies affect the proper functioning of the brain cells which control planning, movement,

making sense of what you see and other important functions of the body. It is most common in people over the age of 65 and more common in men than women. It is a progressive disease, which unfortunately gets worse as more Lewy bodies are formed.

WHAT SYMPTOMS DO LEWY BODIES CAUSE?

As well as the common dementia problems mentioned earlier, Lewy bodies can also cause some very distinct symptoms, which we list here. People have varying combinations of symptoms, depending on where the disease has spread and individual symptoms often get worse over time.

SYMPTOM	DEMENTIA WITH LEWY BODIES	PARKINSON'S DISEASE DEMENTIA
Dementia - Slower thinking speed, problems with understanding, planning, judgment, language and memory loss.	◆ Appears before/within a year of movement problems	◆ Appears after movement problems, later in the disease
Slow and small movement - Stiff limbs, shuffling walk, some tremor - doctors call this parkinsonism.	◆ Appears at the same time or after dementia	◆ Appears before dementia
Extreme swings from alert to confused or sleepy - 'Funny turns', 'tuning out' or feeling 'woozy' may happen without warning and change from hour to hour or day to day and last different lengths of time - doctors call this fluctuating cognition.	◆	◆
Visual hallucinations - Seeing in great detail things that are not there - often children or animals - may be nice or horrible.	◆	◆
Sleep problems - Talking in sleep, vivid/scary dreams, acting out dreams.	◆	◆
Neuroleptic sensitivity - Serious reaction to some kinds of medicine for brain problems.	◆	◆
Changes in personality - Depression and delusions (feeling afraid that something bad is happening or about to happen).	◆	◆
Disturbed vision - Problems with how the brain makes sense of what it sees - objects may seem to move.	◆	◆
Fainting, falls and being unsteady.	◆	◆
Swallowing problems.	◆	◆
Bladder and bowel problems - Infections and losing control of going to the toilet.	◆	◆
Loss or change to senses (smell, hearing, taste).	◆	◆
Face looks blank (can look like a mask).	◆	◆
Other types of hallucinations (hearing, smell).	◆	◆

◆ Core symptoms – the main symptoms Doctors look for when diagnosing Lewy body dementia.
 ✨ Common symptoms