

What is dementia with Lewy bodies (DLB)?

Dementia with Lewy bodies (DLB) is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for around ten per cent of all cases of dementia in older people and tends to be under-diagnosed. Dementia with Lewy bodies is sometimes referred to by other names, including Lewy body dementia, Lewy body variant of Alzheimer's disease, diffuse Lewy body disease, cortical Lewy body disease and senile dementia of Lewy body type. All these terms refer to the same disorder. This factsheet outlines the symptoms of DLB, how it is diagnosed and how it is treated.

Dementia with Lewy bodies appears to affect men and women equally. As with all forms of dementia, it is more prevalent in people over the age of 65. However, in certain rare cases people under 65 may develop DLB.

What are Lewy bodies?

Lewy bodies, named after the doctor who first identified them in 1912, are tiny, spherical protein deposits found in nerve cells. Their presence in the brain disrupts the brain's normal functioning, interrupting the action of important chemical messengers, including acetylcholine and dopamine. Researchers have yet to understand fully why Lewy bodies occur in the brain and how they cause damage.

Lewy bodies are also found in the brains of people with Parkinson's disease, a progressive neurological disease that affects movement. Many people who are initially diagnosed with Parkinson's disease later go on to develop a dementia that closely resembles DLB.

What are the symptoms of dementia with Lewy bodies?

Dementia with Lewy bodies is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

- A person with DLB will usually have some of the symptoms of Alzheimer's and Parkinson's diseases.
- They may experience problems with attention and alertness, often have spatial disorientation and experience difficulty with 'executive function', which includes difficulty in planning ahead and co-ordinating mental activities. Although memory is often affected, it is typically less so than in Alzheimer's disease.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression, and changes in the strength and tone of the voice.

There are also symptoms that are particular to dementia with Lewy bodies. In addition to the symptoms above, a person with DLB may:

- experience detailed and convincing visual hallucinations (seeing things that are not there), often of people or animals
- find that their abilities fluctuate daily, or even hourly
- fall asleep very easily by day, and have restless, disturbed nights with confusion, nightmares and hallucinations
- faint, fall, or have 'funny turns'.

How is dementia with Lewy bodies diagnosed?

Dementia with Lewy bodies can be difficult to diagnose, and this should usually be done by a specialist. People with DLB are often mistakenly diagnosed as having Alzheimer's disease or vascular dementia instead. The diagnosis of DLB is made on the basis of the symptoms - particularly persistent visual hallucinations, fluctuation and the presence of the stiffness and trembling of Parkinson's. New brain-imaging tests can also help.

It is always important to get an accurate diagnosis of dementia, but a proper diagnosis is particularly important in cases of suspected DLB since people with DLB have been shown to react badly to certain forms of medication (see 'DLB and neuroleptics', below).

How is dementia with Lewy bodies treated?

At present, there is no cure for dementia with Lewy bodies. Symptoms such as hallucinations may diminish if challenged, but it can be unhelpful to try to convince the person that there is nothing there. It is sometimes better to try to provide reassurance and alternative distractions. For more information, see Factsheet 520, Hallucinations in people with dementia.

Recent research suggests that the cholinesterase inhibitor drugs used to treat Alzheimer's disease may also be useful in treating DLB, although they are not yet licensed for this use. However, recent guidelines from the National Institute of Clinical Excellence (NICE) do suggest that these drugs should be considered for 'people with DLB who have non-cognitive symptoms causing significant distress to the individual, or leading to behaviour that challenges'.

A recent study also found the drug memantine (Ebixa) to improve general function in DLB although further studies are required to confirm this.

People who are experiencing symptoms such as rigidity and stiffness due to parkinsonism may benefit from anti-Parkinson's disease drugs, although these can make hallucinations and confusion worse. Physiotherapy and mobility aids may also help alleviate these problems.

Dementia with Lewy bodies and neuroleptics

Neuroleptics are strong tranquillisers usually given to people with severe mental health problems. In the past, they have frequently been prescribed to people with dementia. However, it is always preferable to find ways of dealing with a person's distress and disturbance that do not involve medication. Under no circumstances should neuroleptics be prescribed as a substitute for good quality care.

For people with dementia with Lewy bodies, neuroleptics may be particularly dangerous. This class of drugs induce Parkinson-like side-effects, including rigidity, immobility, and an inability to perform tasks or to communicate. Studies have shown that they may even cause sudden death in people with DLB. If a person with DLB must be prescribed a neuroleptic, this should be done with the utmost care, under constant supervision, and should be monitored regularly.

The names of many of the major neuroleptics available are listed below. New drugs are appearing from time to time. The generic name is given first, followed by some of the common proprietary (drug company) names for that particular compound: aripiprazole (Abilify), chlorpromazine (Largactil), clopenthixol (Clopixol), haloperidol (Haldol, Serenace), olanzapine (Zyprexa), promazine quetiapine (Seroquel), risperidone (Risperdal), sulpiride (Dolmatil, Sulparex, Sulpitol), trifluoperazine (Stelazine).

When caring for someone with dementia with Lewy bodies, it is important to be as flexible as possible, bearing in mind that the symptoms of DLB will fluctuate.

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheet

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