

# 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 may account for 10 to 15 per cent of all cases of dementia in older people. This information sheet outlines the symptoms of DLB, how it is diagnosed and how it is treated.

## 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.

Lewy bodies are also found in the brains of people with Parkinson's disease (PD), a progressive neurological disease that affects movement. Some people who are initially diagnosed with PD later go on to develop a dementia that closely resembles DLB. Researchers have yet to understand fully why Lewy bodies occur in the brain.

Dementia with Lewy bodies (DLB) 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.

## Symptoms

DLB 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.

People with DLB will typically have some of the symptoms of Alzheimer's and Parkinson's diseases.

- People who have DLB often experience the memory loss, spatial disorientation and communication difficulties associated with 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.

## Symptoms characteristic of DLB

There are also symptoms that are characteristic of DLB. People with DLB may:

- Find that their abilities fluctuate daily, even hourly

- Faint, fall, or have 'funny turns'
- Experience detailed and convincing visual hallucinations, often of people or animals
- Fall asleep very easily by day and have restless, disturbed nights with confusion, nightmares and hallucinations.

## Who gets DLB?

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

## Diagnosing DLB

DLB can be difficult to diagnose. People are often diagnosed as having Alzheimer's disease or vascular dementia. The diagnosis is made on the basis of the symptoms, particularly visual hallucinations, fluctuation and the presence of the stiffness and trembling of Parkinson's.

While it is always important to get an accurate diagnosis of dementia, 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 below).

## DLB and neuroleptics

Neuroleptics are strong tranquillisers usually given to people with severe mental health problems. In the past they have been prescribed to people with dementia.

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 DLB, 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 when prescribed for people with DLB they may cause sudden death.

If a person with DLB must be prescribed a neuroleptic it should be done with the utmost care, under constant supervision, and it should be monitored regularly.

The following list includes the names of many of the major neuroleptics available. 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.

Chlorpromazine (Largactil)  
 Clopenthixol (Clopixol)  
 Haloperidol (Haldol, Serenace)  
 Olanzapine (Zyprexa)  
 Promazine  
 Quetiapine (Seroquel)

Risperidone (Risperdal)  
Sulpiride (Dolmatil, Sulparex, Sulpitil)  
Trifluoperazine (Stelazine)

## Treatment

At the moment there is no cure for DLB. 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.

Symptoms such as hallucinations may respond to being challenged, but it can sometimes 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.

People who are experiencing rigidity and stiffness owing 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.

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

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