

Dementia with Lewy bodies

About the condition

Dementia with Lewy bodies (DLB) (also known as Lewy body dementia, diffuse Lewy body disease, dementia of Lewy body type or Lewy body variant of Alzheimer's disease) is caused by small, round, deposits of protein that build up inside nerve cells in the brain.

The protein prevents the brain from working properly and affects the function of nerve cells which control thinking and movement. Researchers do not yet know what causes the protein to build up, but work is underway to try and find out why it happens and ways to stop it.

Although DLB is common, it can be difficult to diagnose as a form of dementia, because the symptoms don't always begin with memory problems.

Symptoms

People with DLB will have many of the same symptoms as people with other forms of dementia - a gradual loss of mental abilities, including orientation and memory, reasoning and intelligence, and a progressive decline in the ability to carry out daily tasks.

But there are certain symptoms which are much more likely in DLB, including:

Patchy mental impairment

- some memory problems with periods of normal memory function
- difficulties with things like problem solving and planning
- drowsiness, long periods of staring into space, lethargy or disorganised speech

Hallucinations and delusions

- visual hallucinations e.g. seeing colours, shapes, animals, people, or objects that aren't there
- auditory hallucinations (less common) e.g. hearing music or voices – or involve the other senses of taste, smell and touch
- delusions or false ideas about another person or situation

Neurological symptoms

Symptoms are similar to those of Parkinson's disease, these symptoms are often in just one part of the body, and may include:

- rigidity and stiffness
- difficulty starting movements (known as 'bradykinesia')
- slowness of movement
- a shuffling walk
- tremor
- loss of facial expression
- changes in the strength and tone of the voice

Fluctuating abilities

- be able to carry out a particular task one day, but be completely unable to do it the next day
- episodes of quite sudden severe confusion, which then pass
- varying understanding of their illness
- difficulty perceiving objects

Sleep disturbance

- may fall asleep very easily by day but be wakeful at night
- sometimes not sleeping at all, night after night
- lack of adequate rest can in turn make the person's cognitive problems worse
- some people (rarer symptom) can lose the normal paralysis that we have when we sleep, which means that they may be physically active, talk, or act out dreams in their sleep

Depression

- almost half of those with DLB report symptoms of depression at some point

Diagnosis and tests

If you are worried about DLB it is best to be referred to a specialist (e.g. a geriatrician or an old age psychiatrist) for an early and accurate diagnosis.

There is no specific test for DLB. A doctor will take a detailed history of the symptoms and problems the person is having and use a process of elimination to rule out any other reason the person may experience these symptoms.

As this dementia can often be mistaken for Parkinson's disease, depression or another dementia it is a good idea to write down the changes you have noticed and any other symptoms the person is experiencing – even if you don't think there is a connection.

A brain scan may be used to identify shrinkage of the brain. A Single Photon Emission Computed Tomography (SPECT) scan, which looks at the pattern of blood flow in the brain, can be used to identify some changes in brain function. However, the Lewy bodies themselves can only be seen by looking at brain tissue after death.

The specialist may need to see the person more than once over a period of time before a clear diagnosis is made.

Course of the illness

DLB often starts quite rapidly, with a fast initial decline, although later there may be some levelling off. DLB can last from 5–7 years, although this will vary from person to person.

Treatment and management

There is no cure for DLB at present; however some treatments can be used to improve symptoms.

Anti-psychotic drugs

Anti-psychotic drugs are regularly used for the treatment of restlessness, aggression and psychiatric symptoms common in people with dementia.

Anti-psychotic drugs can have incredibly severe side-effects in people with DLB. They can cause severe, irreversible symptoms of Parkinson's disease, unstable temperature and blood pressure control, breakdown of muscle tissue and in some cases even death.

Due to the possible side-effects, these drugs should not be the first choice of treatment. However, they can be used at a very low dose for a short time, and monitored closely.

If you are caring for someone with DLB who is admitted to hospital or to a care home, you must tell staff that he or she has DLB and make sure that it is recorded in their notes that anti-psychotics should not be prescribed without consulting a specialist.

Cognitive enhancers

Some of the drugs developed for treating people with Alzheimer's disease can be effective in treating people with DLB. They include donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). These drugs are considered by many psychiatrists as the first line of therapy in DLB.

To find out more information on these drugs have a look at the information sheets on our website.

Supportive treatments

- Physiotherapy may help with general fitness and help with flexibility and walking
- Speech therapy may improve low voice volume, poor enunciation, muscular strength, and swallowing difficulties
- Occupational therapy helps maintain skills and promotes functional ability and independence
- Music therapy and aromatherapy may reduce anxiety and improve mood
- Individual and family psychotherapy may be useful for learning strategies to manage emotional and behavioural symptoms

Speak to the person's GP or specialist about referring you to these services.

Useful resources

The Lewy Body Society

Established in June 2006, the Lewy Body Society is the only charity in Europe specifically for people with DLB.

The Lewy Body Society
Unity House
Westwood Park
Wigan
WN3 4HE

Phone: 01942 914000

Email info@lewybody.co.uk

Website: www.lewybody.org

Pick's disease resource group

This support group includes people with DLB.

www.pdsg.org.uk/

Parkinson's Disease Society

Can offer support, particularly around the symptoms of DLB which are similar to Parkinson's disease.

PDS Helpline 0808 800 0303

Email: enquiries@parkinsons.org.uk

Website: www.parkinsons.org.uk



The logo for Alzheimer Scotland's 24-hour Dementia Helpline. It features a purple background with a pink banner at the top left that says "24 HOUR". Below this, the word "Dementia" is written in white, and "Helpline" is written in a large, bold white font. To the right of the text is the Alzheimer Scotland logo, which consists of three stylized human figures in white and pink, with the text "Alzheimer Scotland" and "Action on Dementia" below it. At the bottom of the logo, a pink banner contains the text "Freephone 0808 808 3000" and "Email helpline@alzscot.org".

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