



A Patient's Guide to Dementia with Lewy Body Disease (DLB)

This material is provided
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an educational resource
for patients.



UCSF Weill Institute for Neurosciences
Memory and Aging Center

What is dementia?

When medical professionals use the term “dementia,” it refers to a brain problem that makes it difficult for a person to complete daily tasks without help. Symptoms of dementia vary from person to person and may include memory problems, mood changes, or difficulty walking, speaking, or finding your way. There are many causes for dementia with Lewy body disease (DLB) is one of them.

What is dementia with Lewy body disease?

Dementia with Lewy body disease (DLB) is a condition that causes changes in thinking, behavior, and movement. DLB usually starts with thinking and behavior changes followed by movement problems later. The movement problems in DLB can be similar to those that people with Parkinson's disease have.

What causes DLB?

The cause of DLB is unknown. Scientists know that in DLB there is a large build-up of a protein called alpha synuclein. Some of these clusters are called Lewy bodies. Alpha synuclein occurs normally in the brain, but we do not yet understand what causes it to build up in large amounts. Lewy bodies are also seen in Parkinson's disease. As more and more proteins clump in the nerve cells, the cells lose their ability to function and eventually die. This causes the affected parts of the brain to shrink.

How is age related to DLB?

Most people with DLB start having symptoms between ages 50 and 85, although some people have shown signs earlier.

What happens in DLB?

People with DLB may have trouble focusing, remembering things, staying awake during the day, or staying asleep at night. They may become more frustrated or confused because of lack of sleep. They may also hallucinate and see people, objects, or animals that are not there.

Some people with DLB will need help with walking, while others may have hunched posture or trouble using their hands and feet because of stiff muscles. People with DLB may appear to be better on some days and worse on others.

DLB is a disease that changes with time. A person with DLB can live many years with the disease. Research suggests that a person with DLB may live an average of 5–7 years with the disease, although this can vary from person to person.

Are there medicines to treat DLB?

Though there is no cure for DLB yet, there are medications that help manage the symptoms. These medications are called cholinesterase inhibitors, and they can help if a person with DLB is having memory problems. Some examples of these medicines are

donepezil, rivastigmine, and galantamine. If a person with DLB has movement symptoms they may be treated with medications used for Parkinson's disease, such as levodopa. Sleep problems may be managed by sleep medications including melatonin.

Because people with DLB are usually very sensitive to medications, all medications need to be reviewed with the person's provider to avoid potential contraindication.

How can we manage hallucinations?

It may not be necessary to treat all hallucinations of a person with DLB. Hallucinations are often harmless, and it is okay to allow them to happen, as long as they are not disruptive or upsetting to the person or his/her surroundings. Sometimes, recognizing the hallucination and then switching the topic might be an efficient way of handling frustrations that occur because of a hallucination. If hallucinations need medical treatment, your provider may be able to discuss and suggest some options. However, most medications used to treat hallucinations may make movement symptoms worse.

How can we support the sleep/wake cycle of DLB?

For people with DLB who are confused about the day-night cycle, some daily strategies can be helpful. At night, starting a “lights out” routine that happens at the same hour everyday, where all curtains are closed and lights are turned off, can help the person understand that it is sleep time. During the day, opening the curtains, allowing patients to spend as much time in the daylight as possible, avoiding naps, and organizing stimulating activities, can be helpful. calendars and clocks might also help a person with DLB be less confused about the time of day.

What other things help?

There are various ways to help a person with DLB. Speech therapy may help improve communication between people with DLB and others. Physical therapy may help strengthen and stretch stiff muscles, and help to prevent falls.

Research has shown that physical exercise helps to enhance brain health and improves mood and general fitness. A balanced diet, enough sleep, and limited alcohol intake are other important ways to promote good brain health. Other illnesses that affect the brain, such as diabetes, high blood pressure, and high cholesterol, should also be treated if present.

Resources

Lewy Body Dementia Association: lbda.org

Family Caregiver Alliance: caregiver.org

National Institutes of Health: nih.gov

Research: clinicaltrials.gov