

Department of Clinical Neuropsychology

Understanding Dementia with Lewy Bodies



Dementia is a term that describes progressive difficulty with daily functioning because of a decline in thinking abilities. Dementia with Lewy bodies (DLB) is characterized by changes in alertness, visual hallucinations, and changes in motor function.

Symptoms

Early signs of DLB include changes in thinking ability, such as problems with attention, problem-solving, multitasking, and spatial abilities. Spatial problems can cause difficulty driving and may result in fender-benders, difficulty parking in tight spaces, or hitting the curb more often. These problems sometimes lead to evaluation for visual changes long before a diagnosis of dementia is considered.

Other early signs of DLB include reduced alertness, problems sleeping, visual hallucinations, and movement problems similar to Parkinson's disease. In addition to changes in thinking ability, a person must have one or more of the following symptoms for a diagnosis of DLB to be considered.

- **Daytime sleepiness:** People with DLB may appear drowsy and may sleep for hours during the day. Periods of reduced alertness can occur throughout a single day and may be better or worse from day to day.
- **Sleep disturbances:** People with DLB also experience changes in sleep known as REM sleep behavior disorder (RBD). A person with RBD may act out dreams, talk in their sleep, move around a lot, or fall out of bed. It may be difficult for them to fall asleep or stay asleep. They may also have symptoms of restless leg syndrome.
- **Visual hallucinations:** Typical hallucinations include realistic and detailed images of children or animals. Fortunately, these hallucinations usually do not cause distress.
- **Changes in movement:** Slow movement, tremors, muscle stiffness, and imbalance that may lead to more frequent falls. A person with DLB may have difficulty swallowing, a weak or soft voice, and reduced facial expression. These symptoms are collectively known as parkinsonism because they also occur in Parkinson's disease.

In addition to these symptoms, people with DLB may also experience changes in mood, such as depression, apathy, anxiety, and agitation. They may also experience changes in the body's ability to regulate itself, resulting in sensitivity to heat and cold, dizziness, fainting, sexual dysfunction, urinary incontinence, constipation, and a poor sense of smell.

Causes

Dementia with Lewy bodies is caused by the buildup of an abnormal protein in the brain. The buildup of this protein in brain tissue interferes with normal communication between cells, causing difficulties in attention, memory, mood, and control of movement.

Risk Factors

- Age over 50 years
- Medical conditions including parkinsonism and RBD
- Having a close relative (parent, sibling, or child) with Parkinson's disease or DLB. DLB is not considered a genetic disease, and genetic testing is not used to make a diagnosis. However, certain genes have been linked to an increased risk of developing DLB.

Common Diagnostic Tests

A diagnosis of DLB usually begins with an appointment to see a neurologist. The neurologist will ask about current symptoms, prior functioning, and other health conditions. Also, an MRI of the brain and neuropsychological testing are often done.

An MRI cannot be used to diagnose DLB, but it may be used to rule out other conditions. A special kind of brain imaging called a DaTscan can show how well the dopamine system is functioning. Dopamine is an important brain chemical that helps nerve cells communicate. Having low levels of dopamine in certain brain regions is associated with DLB and other parkinsonian disorders.

Neuropsychological testing uses pencil and paper tests to look at the specific ways in which thinking is impaired. For example, memory problems are uncommon during the early stages of DLB but they may develop later.

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Neuropsychological testing can help show strengths and weaknesses in a person's thinking abilities. When interpreting test results, the doctor looks for certain patterns of performance. These patterns show which parts of the brain are most likely affected.

Treatment

There is no cure for DLB. Instead, treatments aim at controlling the symptoms.

- Medicines used to treat Alzheimer's disease, known as cholinesterase inhibitors, may be prescribed to treat cognitive problems. They may also improve hallucinations and loss of motivation.
- Medicine used to treat Parkinson's disease may improve rigidity and movement. Physical therapy may also be recommended to improve strength and flexibility and to reduce the risk of falls.
- Antidepressants can be used to treat depression and anxiety. Other medicines can be prescribed if hallucinations are distressing or dangerous or if there are significant problems with sleep. Some atypical antipsychotics are also to be avoided in this population.
- Occupational therapy may be recommended for maintaining the skills necessary for independence. Speech therapy may help with voice volume and swallowing difficulty.

Suggestions for Patients

- Take all medications as prescribed. Use a pillbox to keep track of medications.
- Treat other medical conditions to reduce the risk of cognitive and physical decline from other causes.
- Stay socially connected and physically active. These habits help you maintain a healthy brain and improve mood.
- Protect yourself from falls by using a cane or walker and by modifying your environment to make it safer.
 - Remove clutter in the house.
 - Remove throw rugs and low coffee tables that increase risk for tripping.
 - Install a seat and/or grab bars in the shower.
- Consider participating in support groups for individuals with DLB and their caregivers. These groups can be a source of emotional support from others. They can also help you find practical solutions for common frustrations.

Suggestions for Caregivers

- Stick to a routine.
- Use reminders including calendars, lists, or whiteboards.
- Have important conversations in a quiet room free of distractions.
- When possible, attend important appointments and meetings to aid with recall.
- Provide reassurance when an individual with DLB experiences hallucinations. For example, if your loved one is upset by hallucinations, tell them "I know you are upset about those little people in the house, but I have the situation under control."

Resources

Additional resources for patients and caregivers, such as educational materials, support groups, and more, can be found below.

Lewy Body Dementia Association

www.lbda.org

Alzheimer's Association

www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/lewy-body-dementia

Family Caregiver Alliance

www.caregiver.org

Daily Caring

dailycaring.com

National Institute on Aging

www.nia.nih.gov/health/what-lewy-body-dementia

Recommended Books

- *A Caregiver's Guide to Lewy Body Dementia* by Helen and James Whitworth
- *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease* by Pat Snyder
- *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life* by Nancy L. Mace and Peter V. Rabins
- *When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver* by Susan M. McCurry