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What Is Lewy Body Dementia? Causes, Symptoms, and Treatments

Lewy body dementia (LBD) is a disease associated with abnormal deposits of a protein called alpha-synuclein in the brain. These deposits, called Lewy bodies, affect chemicals in the brain whose changes, in turn, can lead to problems with thinking, movement, behavior, and mood. Lewy body dementia is one of the most common causes of [dementia](#).

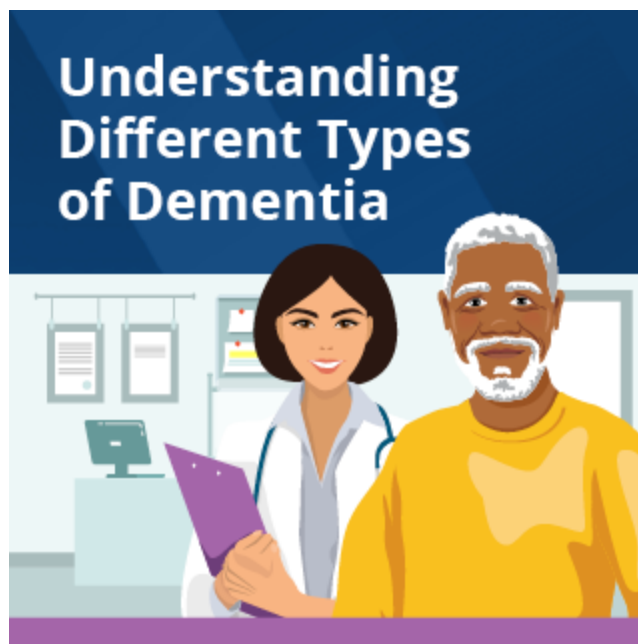
LBD affects more than 1 million individuals in the United States. People typically show symptoms at age 50 or older, although sometimes younger people have LBD. LBD appears to affect slightly more men than women.

[Diagnosing LBD](#) can be challenging. Early LBD [symptoms](#) are often confused with similar symptoms found in other brain diseases or in psychiatric disorders. Lewy body dementia can occur alone or along with other brain disorders.

It is a progressive disease, meaning symptoms start slowly and worsen over time. The disease lasts an average of five to eight years from the time of diagnosis to death, but can range from two to 20 years for some people. How quickly symptoms develop and change varies greatly from person to person, depending on overall health, age, and severity of symptoms.

In the early stages of LBD, symptoms can be mild, and people can function fairly normally. As the disease advances, people with LBD require more help due to a decline in thinking and movement abilities. In the later stages of the disease, they often depend entirely on others for assistance and care.

Some LBD symptoms may respond to treatment for a period of time. Currently, there is no cure for the disease. [Research](#) is improving our understanding of this challenging condition, and advances in science may one day lead to better diagnosis, improved care, and new treatments.



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What Is Lewy Body Dementia?



What are the causes of Lewy body dementia?

The precise cause of LBD is unknown, but scientists are learning more about its biology and genetics. For example, we know that an accumulation of Lewy bodies is associated with a loss of certain neurons in the brain that produce two important chemicals that act as messengers between brain cells (called neurotransmitters). One of these messengers, acetylcholine, is important for memory and learning. The other, dopamine, plays an important role in behavior, cognition, movement, motivation, sleep, and mood.

Scientists are also learning about risk factors for LBD. A risk factor is something that may increase the chance of developing a disease. Some risk factors can be controlled while others cannot. Age is considered the greatest risk factor. No specific lifestyle factor has been proven to increase one's risk for LBD.

Other known risk factors for LBD include certain diseases and health conditions, particularly [Parkinson's disease](#) and REM sleep behavior disorder, which have been linked to a higher risk of LBD.

Having a family member with LBD also may increase a person's risk, though LBD is not considered a genetic disease. Variants in three genes — *APOE*, *SNCA*, and *GBA* — have been associated with an increased risk, but in most cases, the cause is unknown.



Clinical trials on Lewy body dementia

Volunteers are needed for clinical trials that explore how genetics and other factors contribute to LBD risk. By joining one of these studies, you may learn more about how LBD changes the brain and contribute useful information to help other older adults in the future.

Find clinical trials near you

What are Lewy body dementia signs and symptoms?

People with LBD may not have every symptom associated with the disease. Any sudden or major change in functional ability or behavior should be reported to a doctor.

The most common symptoms include changes in [cognition](#), [movement](#), [sleep](#), and [behavior](#).

Cognitive symptoms of Lewy body dementia

LBD causes changes in thinking abilities. These changes may include:

- Visual hallucinations, or seeing things that are not present. Visual hallucinations occur in up to 80 percent of people with LBD, often early on. Nonvisual hallucinations, such as hearing or smelling things that are not present, are less common than visual ones but may also occur.

- Unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes throughout the day. Ideas may be disorganized, unclear, or illogical. These kinds of changes are common in LBD and may help distinguish it from Alzheimer's disease.



- Severe loss of thinking abilities that interfere with daily activities. Unlike in Alzheimer's dementia, [memory problems](#) may not be evident at first but often arise as LBD progresses. Other changes related to thinking may include poor judgment, confusion about time and place, and difficulty with language and numbers.

Movement problems and Lewy body dementia

Some people with LBD may not experience significant movement problems for several years. Others may have them early on. At first, movement symptoms, such as a change in handwriting, may be very mild and easily overlooked.

Movement problems may include:

- Muscle rigidity or stiffness
- Shuffling walk, slow movement, or frozen stance
- Tremor or shaking, most commonly at rest
- Balance problems and repeated falls
- Stooped posture
- Loss of coordination
- Smaller handwriting than was usual for the person
- Reduced facial expression
- Difficulty swallowing
- A weak voice

Lewy body dementia and sleep

[Sleep](#) disorders are common in people with LBD, but are often undiagnosed. A sleep specialist can help diagnose and treat sleep disorders. Sleep-related disorders seen in people with LBD may include:

- [REM sleep behavior disorder](#)
- Excessive daytime sleepiness (sleeping two or more hours during the day)
- Insomnia
- [Restless leg syndrome](#)

Behavioral and mood symptoms of Lewy body dementia

Changes in behavior and mood are possible in LBD and may worsen as the person's thinking abilities decline. These changes may include:

- [Depression](#)
- Apathy, or a lack of interest in normal daily activities or events and less social interaction
- Anxiety and related behaviors, such as asking the same questions over and over or being angry or fearful when a loved one is not present
- Agitation, or restlessness, and related behaviors, such as pacing, hand wringing, an inability to get settled, constant repeating of words or phrases, or irritability
- Delusions, or strongly held false beliefs or opinions not based on evidence. For example, a person may think his or her spouse is having an affair or that relatives long dead are still living.
- Paranoia, or an extreme, irrational distrust of others, such as suspicion that people are taking or hiding things

Other symptoms of Lewy body dementia

People with LBD can also experience significant changes in the part of the nervous system that regulates automatic functions such as those of the heart, glands, and muscles. The person may have:

- Changes in body temperature
- Problems with blood pressure
- Dizziness
- Fainting
- [Frequent falls](#)
- Sensitivity to heat and cold
- Sexual dysfunction
- [Urinary incontinence](#)
- [Constipation](#)
- A poor [sense of smell](#)

Types of Lewy body dementia and diagnosis

LBD refers to either of two related diagnoses — dementia with Lewy bodies (DLB) and Parkinson's disease dementia. Both diagnoses have the same underlying changes in the brain and, over time, people with either diagnosis develop similar symptoms. The difference lies largely in the timing of cognitive (thinking) and movement [symptoms](#).

In DLB, cognitive symptoms develop within a year of movement symptoms. People with DLB have a decline in thinking ability that may look somewhat like [Alzheimer's disease](#). But over time, they also develop movement and other distinctive symptoms of LBD.



In Parkinson's disease dementia, cognitive symptoms develop more than a year after the onset of movement symptoms (for example, tremor or muscle stiffness). Parkinson's disease dementia starts as a movement disorder, with symptoms such as slowed movement, muscle stiffness, tremor, and a shuffling walk. These symptoms are consistent with a diagnosis of Parkinson's disease. Later on, cognitive symptoms of dementia and changes in mood and behavior may arise.

Not all people with Parkinson's disease develop dementia, and it is difficult to predict who will. Many older people with Parkinson's develop some degree of dementia.

Talking to both patients and caregivers helps doctors make a diagnosis. It is important to tell the doctor about any symptoms involving thinking, movement, sleep, behavior, or mood. Also, discuss other health problems and provide a list of all current [medications](#), including prescriptions, over-the-counter drugs, vitamins, and [supplements](#). Certain medications can worsen LBD symptoms.

[Caregivers](#) may be reluctant to talk about a person's symptoms when that person is present. Ask to speak with the doctor privately if necessary. The more information a doctor has, the more accurate a diagnosis can be.

Treatment and care for Lewy body dementia

While LBD currently cannot be prevented or cured, some [symptoms](#) may respond to treatment for a period of time. An LBD treatment plan may involve medications, physical and other types of therapy, and counseling. A plan to make any home safety updates and identify any equipment can make everyday tasks easier.

A skilled care team often can suggest ways to improve quality of life for both people with LBD and their [caregivers](#).

Building a Lewy body dementia care team

After receiving a [diagnosis](#), a person with LBD may benefit from seeing a neurologist who specializes in dementia and/or movement disorders. Your primary doctor can work with other professionals to follow your treatment plan. Depending on an individual's particular symptoms, physical, speech, and occupational therapists, as well as mental health and [palliative care specialists](#), can be helpful.

Support groups are another valuable resource for people with LBD and their caregivers. Sharing experiences and tips with others in the same situation can help people find practical solutions to day-to-day challenges and get emotional and social support.

Lewy body dementia medications

Several drugs and other treatments are available to treat LBD symptoms. It is important to work with a knowledgeable health professional because certain medications can make some symptoms worse.

Coping with cognitive changes



Some [medications used to treat Alzheimer's disease](#) also may be used to treat the cognitive symptoms of LBD. These drugs, called cholinesterase inhibitors, act on a chemical in the brain that is important for memory and thinking. They may also improve hallucinations, apathy, and delusions. The U.S. Food and Drug Administration has approved one Alzheimer's drug, rivastigmine, to treat cognitive symptoms in Parkinson's disease dementia. Several other drugs are being tested as possible treatments for LBD symptoms or to disrupt the underlying disease process.

Treating movement symptoms in Lewy body dementia

LBD-related movement symptoms may be treated with medications used for [Parkinson's disease](#), called carbidopa-levodopa. These drugs can help make it easier to walk, get out of bed, and move around. However, they cannot stop or reverse the disease itself. Side effects of this medication can include hallucinations and other psychiatric or behavioral problems. Because of this risk, physicians may recommend not treating mild movement symptoms with medication. Other Parkinson's medications are less commonly used in people with LBD due to a higher frequency of side effects.

People with LBD may benefit from physical therapy and [exercise](#). Talk with your doctor about what physical activities are best.

Managing sleep disorders in Lewy body dementia

Sleep problems may increase confusion and behavioral problems in people with LBD and add to a caregiver's burden. A physician can order a sleep study to identify any underlying sleep disorders such as [sleep apnea](#), restless leg syndrome, and REM sleep behavior disorder.

REM sleep behavior disorder, a common LBD symptom, involves acting out one's dreams, leading to lost sleep and even injuries to individuals and their sleep partners. Clonazepam, a drug used to control seizures and relieve panic attacks, is often effective for the disorder at very low dosages. However, it can have side effects such as dizziness, unsteadiness, and problems with thinking. Melatonin, a naturally occurring hormone used to treat insomnia, may also offer some benefit when taken alone or with clonazepam.

Excessive daytime sleepiness is also common in LBD. If it is severe, a sleep specialist may prescribe a stimulant to help the person stay awake during the day.

Some people with LBD have difficulty falling asleep. If trouble sleeping at night persists, a physician may recommend a prescription medication. It is important to note that treating insomnia and other sleep problems in people with LBD has not been extensively studied, and that treatments may worsen daytime sleepiness and should be used with caution. Sleep problems can also be addressed by avoiding lengthy naps, increasing daytime exercise, and avoiding caffeine, alcohol, and chocolate late in the day.

Treatment of behavior and mood problems in Lewy body dementia

Behavioral and mood problems in people with LBD can arise from hallucinations, delusions, [pain](#), illness, stress, or anxiety. They may also be the result of frustration, fear, or feeling overwhelmed. The person may resist care or lash out verbally or physically.

Medications are appropriate if the behavior interferes with the person's care or the safety of the person or others. If medication is used, then the lowest possible dose for the shortest period of time is recommended.

The first step is to visit a doctor to see if a medical condition unrelated to LBD is causing the problem. Injuries, fever, [urinary tract](#) or pulmonary infections, pressure ulcers (bed sores), and [constipation](#) can worsen behavioral problems and increase confusion.

Certain medications, such as anticholinergics and antihistamines may also cause behavioral problems. For example, some medications for sleep problems, pain, bladder control, and LBD-related movement symptoms can cause confusion, agitation, hallucinations, and delusions. Similarly, some anti-anxiety medicines can actually increase anxiety in people with LBD. Review your medications with your doctor to determine if any changes are needed.

Cholinesterase inhibitors may reduce hallucinations and other psychiatric symptoms of LBD, but they may have side effects, such as nausea, and are not always effective. However, they can be a good first choice to treat behavioral symptoms. Cholinesterase inhibitors do not affect behavior immediately, so they should be considered as part of a long-term strategy.

[Antidepressants](#) can be used to treat [depression](#) and anxiety, which are common in LBD. Many of them are often well tolerated by people with LBD.

In some cases, antipsychotic medications are necessary to treat LBD-related behavioral symptoms to improve the quality of life and safety of the person with LBD and his or her caregiver. These types of medications must be used with caution because they can worsen movement symptoms and cause severe side effects, such as confusion, extreme sleepiness, and low blood pressure that can result in fainting. In rare cases, a potentially deadly condition called neuroleptic malignant syndrome can occur. Symptoms of this condition include high fever, muscle rigidity, and muscle tissue breakdown that can lead to kidney failure. Report these symptoms to your doctor immediately.

Antipsychotic medications increase the risk of death in all elderly people with dementia but can be particularly dangerous in those with LBD. Doctors, patients, and family members must weigh the risks of antipsychotic use against the risks of physical harm and distress that may occur as a result of untreated behavioral symptoms.

Other treatment considerations

LBD affects the part of the nervous system that regulates automatic actions like blood pressure and digestion. One common symptom is orthostatic hypotension, a drop in blood pressure when standing up that can cause dizziness and fainting. Simple measures such as leg elevation, elastic stockings, and, when recommended by a doctor, increasing salt and fluid intake, can help. If these measures are not enough, a doctor may prescribe medication.

People with LBD are often sensitive to prescription and over-the-counter medications for other medical conditions. People with LBD should tell their doctors about every medication they take, including [prescription and over-the-counter medicines](#), [vitamins](#), and [supplements](#). If surgery is planned and the person with LBD is told to stop taking all medications beforehand, ask the doctor to consult the person's neurologist to develop a plan for careful withdrawal. In addition, talk with the anesthesiologist in advance to discuss medication sensitivities and risks unique to LBD. People with LBD who receive certain anesthetics may become confused or delirious and have a sudden, significant decline in functional abilities, which may become permanent.

Depending on the procedure, possible alternatives to general anesthesia may include a spinal or regional block. These methods are less likely to result in confusion after surgery. Caregivers should also discuss the use of strong pain relievers after surgery because people with LBD can become delirious if these drugs are used too freely.

Lewy body dementia research

Many avenues of research are being explored to improve our understanding of LBD. Some researchers are working to identify the specific differences in the brain between the two types of LBD. Others are looking at the disease's underlying biology, genetics, and environmental risk factors. Still other scientists are trying to identify biomarkers (biological indicators of disease), improve screening tests to aid [diagnosis](#), and research new [treatments](#).

Scientists hope that new knowledge about LBD will one day lead to more effective treatments and even ways to cure and prevent the disorder. Until then, researchers need volunteers with and without LBD for [clinical studies](#).

NIH and other groups help people learn about clinical trials and studies and find research opportunities near them. Visit the following websites for details:

- [Alzheimers.gov Clinical Trials Finder](#) (search using the category "Related Dementias")
- [Lewy Body Dementia Association](#)
- [ClinicalTrials.gov](#)



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Alzheimers.govwww.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

National Institute of Neurological Disorders and Stroke (NINDS)

800-352-9424

braininfo@ninds.nih.govwww.ninds.nih.gov**Lewy Body Dementia Association**

404-935-6444

800-539-9767 (LBD Caregiver Link)

www.lbda.org**Lewy Body Dementia Resource Center**

833-LBDLINE

norma@lbdny.org<https://lewybodyresourcecenter.org>**Mayo Clinic**www.mayoclinic.org/patient-care-and-health-information**MedlinePlus**

National Library of Medicine

www.medlineplus.gov**Michael J. Fox Foundation for Parkinson's Research**

212-509-0995

www.michaeljfox.org**Parkinson's Foundation**

800-473-4636

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