

[alzheimer's disease & dementia](#)

Lewy Body Dementia

Dementia with Lewy bodies shares characteristics with both Alzheimer's and Parkinson's diseases. Here's how to recognize the signs and symptoms and get the treatment you need.



What is Lewy body dementia (LBD)?

While not as well known as some other types of dementia, Lewy body dementia (LBD) is a common type of progressive dementia that according to the Alzheimer's Association, accounts for 5 to 10 percent of dementia cases worldwide. The disease is caused by the accumulation in the brain of abnormal microscopic protein deposits—named Lewy bodies

after the neurologist Frederick Lewy who first observed their effect. These deposits disrupt the brain's normal functioning, causing it to slowly deteriorate.

LBD can take two forms: dementia with Lewy bodies or Parkinson's disease dementia. The difference between them lies mainly in how the disease starts.

In dementia with Lewy bodies, you may have a memory disorder that looks like [Alzheimer's](#) but later develop movement and other distinctive problems, such as hallucinations.

In Parkinson's disease dementia, you may initially have a movement disorder that looks like [Parkinson's](#) but later also develop dementia symptoms.

Over time, though, both diagnoses will appear the same. Most people with LBD develop a similar spectrum of problems that include variations in attention and alertness, recurrent visual hallucinations, shuffling gait, tremors, and blank expression, along with various sleep disorders.

Lewy body dementia can bear a striking resemblance to [Alzheimer's disease](#) or [Parkinson's disease](#), but treatment can be very different, making early recognition of the signs and symptoms key to managing the condition. And while there is currently no cure for LBD, that doesn't mean there isn't hope. Important early treatment and self-help techniques can help to extend your independence and maintain your quality of life for longer.

Signs and symptoms of Lewy body dementia

As with Alzheimer's disease or Parkinson's disease, the symptoms of Lewy body dementia worsen over time, with intellectual and motor functions deteriorating, typically over several years. Despite the overlaps, however, there are symptoms that indicate the disorder is indeed LBD and not another condition.

While patients with LBD lose cognitive function, they are less prone to the short-term memory loss associated with Alzheimer's disease. More commonly, they experience greater problems with executive functions of planning, decision-making, and organization, as well as difficulties with visual perception, such as judging and navigating distances. This can cause you to fall or faint frequently or become lost in familiar settings. Lewy body dementia can also cause sleep disturbances, including insomnia and daytime sleepiness.

If you have Lewy body dementia, you will also exhibit at least two of four core features:

Changes or “fluctuations” in awareness and concentration. You swing from a state of alertness to appearing drowsy, confused, or staring into space. These episodes can be unpredictable and last anywhere from a few seconds to several hours.

Spontaneous Parkinson’s-like motor symptoms, such as slowness of movement, rigid muscles, tremor, lack of facial expression, or abnormal gait.

Recurrent visual hallucinations or delusions, such as seeing shapes, colors, people, or animals that aren’t there or conversing with deceased loved ones.

REM sleep behavior disorder symptoms, in which you act out your dreams during sleep—physically moving limbs, sleep talking, screaming, hitting, or even getting up and engaging in daytime activities.

In short, if you or a loved one are experiencing cognitive decline without the archetypal problems with recent memory, it may indicate that you’re dealing with Lewy body dementia rather than another type of dementia.

Other common symptoms

In addition to cognitive decline, hallucinations, motor and sleep problems, you may also experience:

1. **Depression.**
2. **Increasing problems handling the tasks of daily living.** Tasks that used to be simple may become difficult for a person with LBD.
3. **Fluctuations in autonomic processes.** This includes blood pressure, body temperature, urinary difficulties, constipation, and difficulty swallowing.

Parkinson’s, Alzheimer’s, and Lewy body dementia

Since Lewy body dementia is commonly misdiagnosed for both Parkinson’s and Alzheimer’s, it is helpful to understand how these diseases overlap.

Overlapping symptoms of Parkinson’s, Alzheimer’s, and Lewy body dementia

Parkinson’s and Lewy body
dementia

Alzheimer’s and Lewy body
dementia

Overlapping symptoms of Parkinson's, Alzheimer's, and Lewy body dementia

Some of the **motor symptoms** found in both

Parkinson's and Lewy body patients include:

- tremors
- muscle stiffness
- difficulties with balance
- shuffling gait
- stooped posture
- slow movements
- [restless leg syndrome](#)

Some of the **cognitive symptoms** found in both

Alzheimer's and Lewy body's patients include:

- behavioral changes
- decreased judgment
- confusion and temporal/spatial disorientation
- difficulty following directions
- decreased ability to communicate

Diagnosing LBD

Since many of the symptoms can also be caused by other conditions, confirming a diagnosis of Lewy body dementia can be challenging. To help your doctor, take a friend or loved one along to appointments and keep detailed notes about how and when your symptoms occur.

Since the Lewy bodies themselves can be identified only by autopsy, an accurate diagnosis relies heavily on physician awareness of the defining characteristics of the disease. Your doctor or specialist may:

Assess your symptoms, such as how long you have had memory problems and the presence of sleep disturbances or hallucinations.

Assess your mental abilities, such as language, organization, and communication skills, attention span, and ability to follow instructions.

Conduct a physical examination, including blood tests and review of current medications, to rule out other causes of symptoms.

Conduct brain scans. While a brain scan can detect mental deterioration, not the actual Lewy bodies, it may still be helpful in diagnosis.

Coping with a diagnosis

[Being diagnosed with dementia](#) can be an overwhelming experience. While there is no cure at present for LBD, or any medications aimed at specifically treating LBD, doctors are able

to treat many of its symptoms. There are also a number of self-help strategies that can help improve symptoms.

If you've been diagnosed with LBD, it's normal to feel many strong and painful emotions, including anger, fear, and uncertainty about the future.

Take time to adjust. As with any major life change, it's important to give yourself time to adjust. Expect ups and downs as you do. You may feel that you've come to terms with your new situation for a while, and then suddenly feel overwhelmed by stress again.

Reach out for support. Living with Lewy body dementia is not easy, but there is help for this journey. The more support you have from family and friends, the better you'll be able to cope with symptoms.

Talk to your loved ones about your wishes. It's never easy to talk about how you want your healthcare handled when you're unable to make decisions for yourself. But it's important to let your loved one know what is important to you. Thinking about your choices today can improve your quality of life in the future and ease the burden on your family.

Slowing the progression of symptoms

The same healthy lifestyle changes that are used to prevent dementia can also be useful in slowing the advancement of LBD symptoms.

1. **Get regular exercise** to stimulate your brain's ability to maintain old connections, make new ones, and slow deterioration of cognitive abilities.
2. **Social engagement**, connecting face-to-face with others, can help improve your cognitive function will be.
3. **Eating a brain-healthy diet** can help reduce inflammation and promote better communication between brain cells.
4. **Mental stimulation**, learning new things, and challenging your brain can help strengthen your cognitive skills.
5. **Getting quality sleep** can flush out brain toxins and avoid the build-up of damaging plaques.
6. **Managing stress** can help slow shrinking to a key memory area of the brain and protect nerve cell growth.

To learn more about putting these strategies into action, see [Preventing Alzheimer's](#)

[Disease](#).

Self-help tips for living with Lewy body dementia

Because the treatment for LBD focuses primarily on symptom management, it's helpful to take as proactive an approach as possible right away. This means reaching out to loved ones for support, working with your physician to control symptoms, and making lifestyle changes to accommodate the effects of the disease.

Become informed. Learn as much as you can about dementia with Lewy bodies and how it is likely to specifically affect you, given your health history, age, and lifestyle. The more you know, the more control you'll feel and the better you'll be able to cope with symptoms.

Reduce stress. Stress and anxiety can make many symptoms of LBD worse. To find ways to relax, experiment with relaxation techniques such as music therapy, meditation, and deep breathing exercises. Aromatherapy, massage therapy, and pet therapy, involving visits from specially trained animals, can also help to relieve stress and improve your mood.

Treat depression. Report [symptoms](#) to your doctor and take steps to address the problem. Receiving treatment for depression can make it easier to handle the other challenges of LBD.

Avoid isolation. Reach out to family and friends for emotional support and join a support group for patients with Lewy body dementia. Talking to other people facing the same challenges can help with feelings of isolation and depression and provide a wealth of helpful information on coping with LBD.

Exercise can not only improve physical function, it can help relieve stress and boost your mood. Any type of physical activity that raises your heart rate can be beneficial, so find the activities that appeal to you.

Enjoy games and puzzles. Playing cards or word games such as Scrabble, or completing crossword and Sudoku puzzles can exercise your brain and may help slow cognitive decline.

Limit caffeine and avoid daytime napping. Along with getting regular exercise during the day, these steps can help prevent nighttime restlessness.

Do things every day that add joy to your life. People with dementia are still capable of

experiencing and providing enjoyment and connection. Nourish your spirit by doing things that bring you pleasure, whether it's spending time in nature, enjoying the arts, playing with your grandkids, or pursuing a favorite hobby.

Find meaning and purpose. Continue activities that were important to you before your diagnosis or find new ways to invest yourself. You might consider [volunteering for a cause](#) that's important to you, involving yourself in a religious community, or even caring for your pets—anything that makes you feel needed and fulfilled.

Other alternative treatments for LBD

- **Physical therapy** options include cardiovascular, strengthening, and flexibility exercises, as well as gait training. Physicians may also recommend general physical fitness programs such as aerobic, strengthening, or water exercise.
- **Speech therapy** may be helpful for low voice volume and poor enunciation. Speech therapy may also improve muscular strength and swallowing difficulties.
- **Occupational therapy** may help maintain skills and promote function and independence. In addition to these forms of therapy and treatment, music and aroma therapy can also reduce anxiety and improve mood.
- **Individual and family psychotherapy** can be useful for learning strategies to manage emotional and behavioral symptoms and to help make plans that address individual and family concerns about the future.

Source: LBDA

Treatment

Treatments for LBD are aimed at controlling the cognitive, motor, and psychiatric problems associated with the disorder, including hallucinations, depression, and sleep disturbances.

Medication

Medications for the treatment of LBD can offer relief of cognitive, movement, and behavioral symptoms, and may include the same drugs used to treat Alzheimer's disease and Parkinson's disease. However, some people with LBD can have extremely adverse reactions to certain medications and may react very differently than patients with Alzheimer's or Parkinson's. Some medications can even worsen LBD symptoms, another

reason why accurate early diagnosis is so important.

Work closely with your doctor to find the drugs and doses that are most effective for you and always speak up about any side-effects you or your loved one experiences.

- Your doctor may use cholinesterase inhibitors, such as donepezil and rivastigmine, to treat the cognitive symptoms of Lewy body dementia. They can also be effective in treating visual hallucinations and other psychiatric symptoms.
- Levodopa may help with movement and rigidity in some people with LBD.
- Melatonin or clonazepam can help treat REM Sleep Behavior Disorder and other sleeping problems.
- [Antidepressants](#) such as SSRIs may be used to help treat depression, which is common with LBD.

Dementia with Lewy bodies and neuroleptics

Neuroleptics, or antipsychotics, are strong tranquilizers sometimes prescribed for people with dementia to treat hallucinations or other behavior problems. However, if taken by people with LBD, neuroleptics may be particularly dangerous. This class of drugs can induce Parkinson-like side-effects, including rigidity, immobility, and an inability to perform tasks or to communicate.

If you or your loved one with Lewy body dementia is not unduly distressed by the hallucinations, it may be better to tolerate them rather than endure the side effects of the medication. If, however, you and your doctor decide to use a neuroleptic, this should be done with the utmost care and monitored carefully and regularly.

According to Lewy Body Dementia Association:

Up to 50% of patients with LBD who are treated with any antipsychotic medication may experience severe neuroleptic sensitivity, such as worsening cognition, heavy sedation, increased or possibly irreversible Parkinsonism, or symptoms resembling neuroleptic malignant syndrome (NMS), which can be fatal. (NMS causes severe fever, muscle rigidity and breakdown that can lead to kidney failure).

Caring for someone with Lewy body dementia

Caring for someone with LBD, or any form of dementia, is hugely challenging. Just as LBD can impact every aspect of a person, caring for someone with the disease can impact every aspect of your daily life. You'll likely face tests of stamina, problem solving, and resiliency. However, your caregiving journey can also be an intensely rewarding experience as long as you take care of yourself and get the support that you need.

How to help someone manage Lewy body dementia

When it comes to helping someone manage the symptoms of LBD, small things can often make a big difference.

Create a routine. It can help someone with LBD to have predictable routines, especially around meal times and sleep times.

Establish a nighttime ritual. Try to establish bedtime rituals that are calming and away from the noise of television, meal cleanup, and active family members. Limiting caffeine consumption and daytime napping, and encouraging exercise can help curb restlessness at night.

Modify tasks. Break tasks into easier steps and focus on success, not failure.

Walk together. Taking a walk with the patient with LBD is a win-win activity. Being outdoors and exercising is vital for the health and state of mind for both the patient and you.

Strengthen senses. Have a doctor evaluate each the patient's five senses in order to identify and treat any abnormalities. Then ask about exercises to improve them.

Make lifestyle changes. To help minimize the risk of fall-related injuries, you can help stabilize blood pressure. Help your loved one stay well hydrated, exercise, take in adequate sodium (salt), avoid prolonged bed rest, and stand up slowly.

Tips for managing behavioral changes

One of the major challenges of caring for a loved one with dementia can be coping with the troubling behavioral changes that often occur. As a caregiver, you can't change the person with dementia, but you can employ strategies to modify or better accommodate any problem

behaviors.

- Remember, the person with dementia is not being deliberately difficult. Your loved one's sense of reality may be different to yours, but it's still very real to them.
- Troubling behavior can often be a reaction to stress or a frustrated attempt to communicate. Try to establish why the patient is stressed or what is triggering the behavior. Is your loved one hungry, thirsty, tired, in pain, frustrated?
- Speak calmly, softly and use body language. A dementia patient will often respond to your facial expression, tone of voice, and body language far more than the words you choose. Use eye contact, a smile, or reassuring touch to help convey your message.
- The environment and atmosphere you create while caregiving can help a dementia patient feel calm and safe. Modify the environment to reduce potential stressors such as loud or unidentifiable noises. Try to remain flexible, patient, and relaxed. If you find yourself becoming anxious or losing control, take a time out to cool down.

For more, see [Alzheimer's and Dementia Behavior Management](#).

Authors: Lawrence Robinson and Jeanne Segal, Ph.D.

Last updated: August 2021

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Support groups and caregiver resources

Support groups

[Local LBD Support Groups](#) - Offers a list of support groups in over 30 states and Canada (Lewy Body Dementia Association)

[Dementia Services in the UK](#) -

Includes a list of resources for local services, including support groups. (Lewy Body Society)

[Dementia Support in Australia](#) - List of regional dementia support groups. (Ozcare)

Caregiver resources

[LBD Caregiver Link](#) - In the U.S., talk to a volunteer at 800-539-9767 for referrals to caregiving programs and services or other practical or emotional support. (Lewy Body Dementia Association)

[Carers](#) - Links to information, helplines, and other caregiving resources in the UK. (Lewy Body Society)

[Lewy Body Disease Help Sheets](#) - In Australia, call the National Dementia Helpline on 1800 100 500 for help, information, resources and support. (Dementia Australia)