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Treatment and Management of Lewy Body Dementia

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While Lewy body dementia (LBD) currently cannot be prevented or cured, some [symptoms](#) may respond to treatment for a period of time. A comprehensive treatment plan may involve medications, physical and other types of therapy, and counseling. Changes to make the home safer, equipment to make everyday tasks easier, and social support are also very important.

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

Building a Care Team

After receiving a [diagnosis](#), a person with LBD may benefit from seeing a neurologist who specializes in dementia and/or movement disorders. A good place to find an LBD specialist is at a



dementia or movement disorders clinic in an academic medical center in your community. If such a specialist cannot be found, a general neurologist should be part of the care team. Ask a primary care physician for a referral.

Depending on an individual's particular symptoms, other professionals may also be helpful:

- **Physical therapists** can help with movement problems through cardiovascular, strengthening, and flexibility exercises, as well as gait training and general physical fitness programs.
- **Speech therapists** may help with low voice volume, voice projection, and swallowing difficulties.
- **Occupational therapists** help identify ways to more easily carry out everyday activities, such as eating and bathing, to promote

independence.

- **Music or expressive arts therapists** may provide meaningful activities that can reduce anxiety and improve well-being.
- **Mental health counselors** can help people with LBD and their families learn how to manage difficult emotions and behaviors and plan for the future.
- **Palliative care specialists** can help improve a person's quality of life by relieving disease symptoms at any stage of illness.

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

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. Some symptoms can improve with nondrug treatments.

Cognitive Symptoms

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 behavioral symptoms.

The U.S. Food and Drug Administration (FDA) approves specific drugs for certain uses after rigorous testing and review. The FDA has approved one Alzheimer's drug, rivastigmine (Exelon®), to treat cognitive symptoms in Parkinson's disease dementia. This and other Alzheimer's drugs can have side effects such as nausea and diarrhea.

Getting Treatment

Kamar, grandfather of five, was a highly educated executive with a background in the research, development, and field testing of aircraft engines. When he retired at 67, his wife, Manjit, noticed that he had problems with complex mental activities and that his executive abilities had declined. He also had trouble with tasks involving a sequence of steps. His doctor prescribed a medication for the cognitive symptoms, which was helpful. It has been 6 years since Kamar was diagnosed, and Manjit credits the medication for helping him have a better quality of life.

Movement Symptoms

LBD-related movement symptoms may be treated with a [Parkinson's](#) medication called carbidopa-levodopa (Sinemet®, Parcopa®, Stalevo®). This drug can help improve functioning by making it easier to walk, get out of bed, and move around. However, it cannot stop or reverse the progress of the disease.

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. If prescribed, carbidopa-levodopa usually begins at a low dose and is increased gradually. Other Parkinson's medications are less commonly used in people with LBD due to a higher frequency of side effects.

A surgical procedure called deep brain stimulation, which can be very effective in treating the movement symptoms of Parkinson's disease, is not recommended for people with LBD because it can result in greater cognitive impairment.

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

Sleep Disorders

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 sleep partners. Clonazepam (Klonopin®), 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 may have difficulty falling asleep. If trouble sleeping at night (insomnia) persists, a physician may recommend a prescription medication to promote sleep. 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.

Certain sleep problems can be addressed without medications. Increasing daytime exercise or activities and avoiding lengthy or frequent naps can promote better sleep. Avoiding alcohol, caffeine, or chocolate late in the day can help, too. Some over-the-counter medications can also affect sleep, so [review all medications and supplements](#) with a physician.

Behavioral and Mood Problems

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

Caregivers must try to be patient and use a variety of strategies to handle such challenging behaviors. Some behavioral problems can be managed by making changes in the person's environment and/or treating medical conditions. Other problems may require medication.

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. Increased confusion can also occur.

Certain medications used to treat LBD symptoms or other diseases may also cause behavioral problems. For example, some sleep aids, pain medications, bladder control medications, and drugs used to treat 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.

Not all behavioral problems are caused by illness or medication. A person's surroundings—including levels of stimulation or stress, lighting, daily routines, and relationships—can lead to behavior issues. Caregivers can alter the home environment to try to minimize anxiety and stress for the person with LBD. In general, people with LBD benefit from having simple tasks, consistent schedules, regular exercise, and adequate sleep. Large crowds or overly stimulating environments can increase confusion and anxiety.

[Hallucinations and delusions](#) are among the biggest challenges for LBD caregivers. The person with LBD may not understand or accept that the hallucinations are not real and become agitated or anxious. Caregivers can help by responding to the fears expressed instead of arguing or responding factually to comments that may not be true. By tuning in to the person's emotions, caregivers can offer empathy and concern, maintain the person's dignity, and limit further tension.

Cholinesterase inhibitors may reduce hallucinations and other psychiatric symptoms of LBD. These medications 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 part of a long-term strategy.

Seeing Things

John, 58, started seeing small children outside the window who were not there. Eventually, he began talking with some of these children, whom he thought were visiting the house. These hallucinations never scared or threatened John, and they seemed to give him companionship and

entertainment. His wife Linda consulted a doctor, who said that since the hallucinations were not disruptive, no medication was needed. He advised Linda not to argue with her husband about whether or not the children were there.

[Antidepressants](#) can be used to treat [depression](#) and anxiety, which are common in LBD. Two types of antidepressants, called selective serotonin reuptake inhibitors and norepinephrine reuptake inhibitors, are often well tolerated by people with LBD.

In some cases, antipsychotic medications are necessary to treat LBD-related behavioral symptoms to improve both 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 cause severe side effects and can worsen movement symptoms.

If antipsychotics are prescribed, it is very important to use the newer kind, called *atypical* antipsychotics. These medications should be used at the lowest dose possible and for the shortest time possible to control symptoms. Many LBD experts prefer quetiapine (Seroquel®) or clozapine (Clozaril®, FazaClo®) to control difficult behavioral symptoms.

Typical (or traditional) antipsychotics, such as haloperidol (Haldol®), generally should **not** be prescribed for people with LBD. They can cause dangerous side effects.

Warning About Antipsychotics

People with LBD may have severe reactions to or side effects from antipsychotics, medications used to treat delusions, hallucinations, or agitation. These side effects include increased confusion, worsened parkinsonism, extreme sleepiness, and low blood pressure that can result in fainting (orthostatic hypotension). Caregivers should contact the doctor if these side effects continue after a few days.

Some antipsychotics, including olanzapine (Zyprexa®) and risperidone (Risperdal®), should be avoided, if possible, because they are more likely than others to cause serious side effects.

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 elderly people with dementia, including 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, low blood pressure 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.

[Urinary incontinence](#) (loss of bladder control) should be treated cautiously because certain medications used to treat this condition may worsen cognition or increase confusion. Consider seeing a urologist. Constipation can usually be treated by exercise and changes in diet, though laxatives and stool softeners may be necessary.

People with LBD are often sensitive to prescription and over-the-counter medications for other medical conditions. Talk with your doctor about any side effects seen in a person with LBD.

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 in developing a plan for careful withdrawal. In addition, be sure to 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, since people with LBD can become delirious if these drugs are used too freely.

Vitamins and Supplements

The use of [vitamins and supplements](#) to treat LBD symptoms has not been studied extensively and is not recommended as part of standard treatment. Vitamins and supplements can be dangerous when taken with other medicines. People with LBD should tell their doctors about every medication they take. Be sure to [list prescription and over-the-counter medicines, as well as vitamins and supplements](#).

For More Information About Treating and Managing LBD

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

1-800-438-4380 (toll-free)

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Lewy Body Dementia Association

1-404-935-6444

1-800-539-9767 (toll-free LBD Caregiver Link)

www.lbda.org

Eldercare Locator

1-800-677-1116 (toll-free)

www.eldercare.gov

National Institute of Neurological Disorders and Stroke

1-800-352-9424 (toll-free)

braininfo@ninds.nih.gov

www.ninds.nih.gov

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