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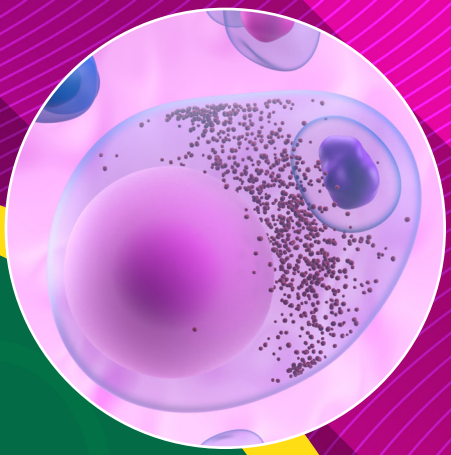

Lewy Body Dementia

Information for Patients, Families, and Professionals

LEARN ABOUT:

- Dementia with Lewy bodies
- Parkinson's disease dementia

National Institute on Aging

National Institute of Neurological Disorders and Stroke

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Introduction

Lewy body dementia (LBD) is a complex and challenging brain disorder. LBD is characterized by the presence of Lewy bodies in the brain and cognitive decline that worsens over time. LBD also affects other parts of the body and bodily functions in ways that scientists are trying to understand more fully. LBD's many possible symptoms make it hard to do everyday tasks that once came easily.

Although less is known about LBD than other forms of dementia, it is not a rare disorder. LBD has two forms — dementia with Lewy bodies and Parkinson's disease dementia. Although they have some differences, the two forms are related. Most people living with either form of the disorder are older adults, and they experience disabling changes in their ability to think and move due to the disorder.

There is currently no cure for LBD. While researchers seek better ways to treat and cure the disorder, people with LBD and their families continue to face challenges to get an accurate diagnosis, find the best treatments, and manage at home and in their communities.

This booklet is meant to help people living with LBD, their families, caregivers, and professionals learn more about the disease and find resources for coping. It explains what is known about the different forms of LBD and how they are diagnosed. Most importantly, it describes how to treat and manage this difficult disease, with practical advice for both people with LBD and their caregivers. A list of resources begins on page 46.

The Basics of 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. These changes, in turn, can lead to problems with thinking, movement, behavior, mood, and other body functions.

Dementia is a loss of thinking abilities that interferes with a person's ability to perform daily activities, such as household tasks, personal care, and handling finances.

Diagnosing LBD can be challenging. Early LBD symptoms are often confused with similar symptoms found in other brain diseases like Alzheimer's disease. Some early symptoms of LBD can be mild and include changes in mood, vision, sleep, and bowel movements. Additionally, LBD can occur alone or along with other brain disorders.

Who Is Affected by LBD?

LBD typically begins at age 50 or older, although sometimes younger people may have it. LBD appears to affect slightly more men than women.

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

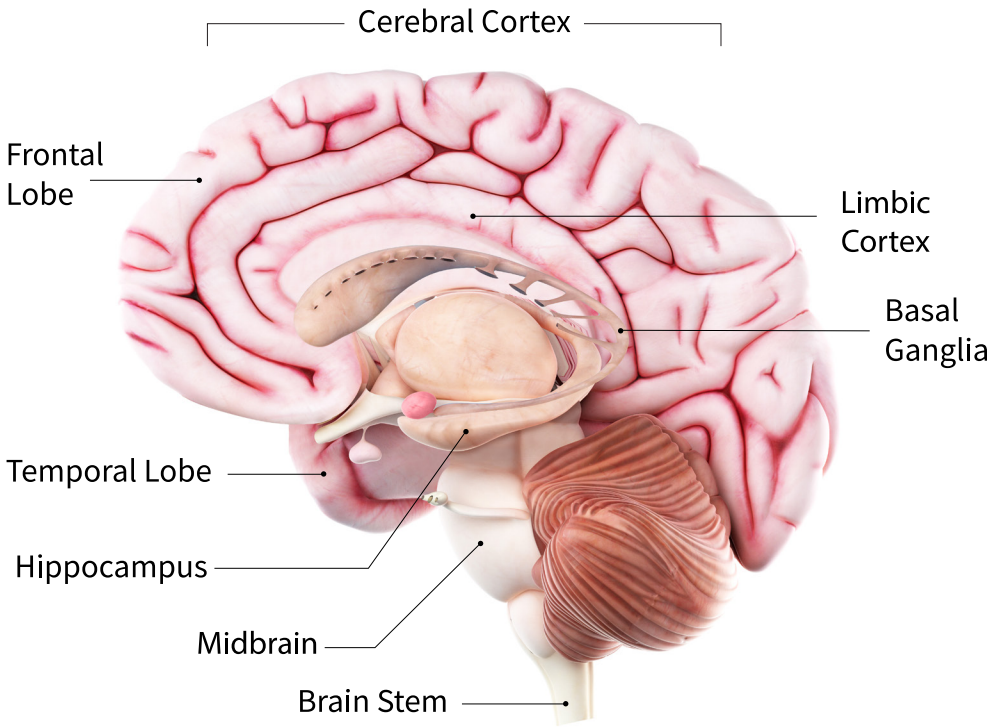
In the early stages of LBD, sometimes before a diagnosis is made, symptoms can be mild and have less impact on daily functioning. As the disease advances, people with LBD require more and more help with daily activities due to a decline in thinking and movement abilities. In the later stages of the disease, people may depend entirely on others for assistance and care.

Some LBD symptoms may respond to treatment, though responses vary. Currently, there is no cure for the disease. Research is improving our understanding of LBD, and advances in science may one day lead to better diagnosis, improved care, and new treatments.

What Are Lewy Bodies?

Lewy bodies are named for Dr. Friedrich Lewy, a German neurologist. In 1912, he discovered abnormal protein deposits that disrupt the brain's normal functioning in people with Parkinson's disease. These abnormal deposits, called Lewy bodies, are named after him.

Lewy bodies are made of a protein called alpha-synuclein. In the healthy brain, alpha-synuclein plays a number of important roles in neurons (nerve cells), especially at synapses, where brain cells communicate with each other. In LBD, alpha-synuclein forms into clumps inside neurons, starting in specific regions of the brain. This process causes neurons to work less effectively and, eventually, to die. The activities of certain brain chemicals important to brain function are also affected. The result is widespread damage to certain parts of the brain and a decline in abilities controlled by the affected brain regions.



In LBD, Lewy bodies affect several different brain regions, including the:

- Cerebral cortex, which controls many functions, including information processing, perception, thought, and language
- Limbic cortex, which plays a major role in emotions and behavior
- Hippocampus, which is essential to forming new memories
- Midbrain and basal ganglia, which are involved in movement
- Brainstem, which is important in regulating sleep and maintaining alertness
- Olfactory pathways, which are important in recognizing smells

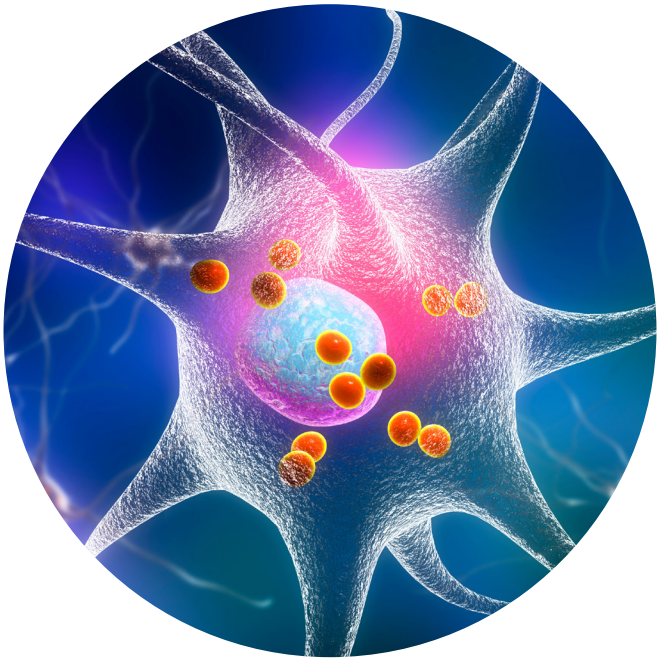
Nervous system tissue outside the brain, including nerves in the intestines, heart, sex organs, and salivary glands, can be affected by LBD as well. This may lead to symptoms such as constipation, dizziness with changing position, sexual dysfunction, or drooling.

Causes and Risk Factors

The precise cause of LBD is unknown, but scientists are learning more about its biology and genetics. For example, they know that an accumulation of Lewy bodies is associated with a loss of certain neurons in the brain that produce important neurotransmitters, which are chemicals that act as messengers between brain cells.

One of these neurotransmitters, acetylcholine, is important for memory and learning. Another neurotransmitter — dopamine — plays a key role in behavior, thinking ability (cognition), movement, motivation, sleep, and mood.

Scientists are also learning about risk factors for LBD. Age is considered the greatest risk factor, with most people developing the disorder over age 50. A higher number of men are also affected by LBD.



Other known risk factors for LBD include the following:

- **Diseases and health conditions:** Certain diseases and health conditions, particularly REM sleep behavior disorder and loss of smell, are linked to a higher risk of LBD.
- **Genetics:** While having a family member with LBD may increase a person's risk, LBD is not typically considered a hereditary disease. A small percentage of families with dementia with Lewy bodies (a form of LBD) have certain genetic variants that may be associated with disease risk. However, in most cases, the cause of LBD is unknown. At this time, no genetic test can accurately predict whether someone will develop LBD. Future genetic research may reveal more information about causes and risk.
- **Lifestyle:** No specific lifestyle factor has been proven to increase one's risk for LBD. However, some studies suggest that a healthy lifestyle, including regular exercise, mental stimulation, and a healthy diet, might reduce the risk of developing age-associated dementias.

Common Symptoms

People with LBD may not have every LBD symptom, and the severity of symptoms can vary greatly from person to person. Throughout the course of the disease, any sudden or major change in functional ability, symptoms, or behavior should be reported to a doctor.

The most common symptoms of LBD include changes in cognition, movement, sleep, behavior, and body functions that happen without you thinking about them (autonomic functions), such as dizziness on standing (caused by low blood pressure) and constipation.

Cognitive Symptoms

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

- **Dementia:** Loss of thinking abilities that interferes with a person's capacity to perform daily activities. Dementia is a primary symptom of LBD and usually includes trouble with attention, visual and spatial abilities (judging distance and depth or misidentifying objects), reasoning, and executive functioning (multitasking and problem solving). Memory problems may not be evident at first, but they often become more apparent over time. Dementia can also include changes in mood and behavior, poor judgment, loss of initiative, confusion about time and place, and difficulty with language and numbers.

- **Cognitive fluctuations:** Unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes throughout the day. A person with LBD may stare into space for periods of time, seem drowsy and lethargic, or sleep for several hours during the day despite getting enough sleep the night before. Their flow of ideas may be disorganized, unclear, or illogical at times. The person may seem better one day, then worse the next. These cognitive fluctuations are common in LBD but are not always easy for a doctor to identify.
- **Hallucinations:** Seeing or hearing things that are not present. Visual hallucinations occur in most people with LBD, often early in the disease. They are typically realistic and detailed, such as images of children or animals. Hallucinations based in other senses, such as hearing, are less common than visual ones but may also occur. Hallucinations that are not disruptive may not require treatment. However, if they are frightening or lead to dangerous behavior (for example, if the person attempts to fight a perceived intruder), then a doctor may prescribe medication.

Movement Symptoms

Some people with LBD may not experience significant movement problems for several years. Others may have them early on. Some people with dementia with Lewy bodies may never develop movement symptoms. At first, signs of these problems may be very mild and easily overlooked. Movement symptoms may include:

- Slowness of movement
- Muscle rigidity or stiffness
- Shuffling walk or frozen stance
- Tremor or shaking, most commonly at rest
- Balance problems and falls

- Stooped posture
- Loss of coordination
- Smaller handwriting than was usual for the person
- Reduced facial expression
- Difficulty swallowing
- Weak voice

Sleep Disorders

Sleep disorders are common in people with LBD but are often undiagnosed. A sleep specialist can play an important role on a treatment team, helping to identify and treat sleep disorders. Sleep-related disorders seen in people with LBD may include:

- **REM sleep behavior disorder:** A condition in which a person seems to act out dreams. It may include vivid dreaming, talking in one's sleep, violent movements, or falling out of bed. The dreams often involve the perception of being chased or attacked by something or someone. This can be challenging for both the person with LBD and the caregiver. REM sleep behavior disorder appears in some people years before other LBD symptoms.
- **Excessive daytime sleepiness:** Sleeping two or more hours during the day.
- **Insomnia:** Difficulty falling or staying asleep or waking up too early.
- **Restless leg syndrome:** A condition in which a person, while resting, feels the urge to move his or her legs to stop unpleasant or unusual sensations. Walking or moving usually relieves the discomfort temporarily, but the sensations return when at rest.

Behavioral and Mood Symptoms

Changes in behavior and mood are possible in LBD and may vary from person to person, depending on their level of cognitive decline. These changes may include:

- **Depression:** A persistent feeling of sadness, inability to enjoy activities, or trouble with sleeping, eating, and other everyday activities.
- **Apathy:** A lack of interest in normal daily activities or events; less social interaction.
- **Anxiety:** Intense apprehension, uncertainty, or fear about a future event or situation. A person may ask the same questions over and over or be angry or fearful when a loved one is not present.
- **Agitation:** Restlessness, including pacing, hand wringing, an inability to get settled, constant repeating of words or phrases, or irritability.
- **Delusions or misperceptions:** 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. Capgras syndrome, in which the person believes a relative or friend has been replaced by an imposter, may also occur.
- **Paranoia:** An extreme, irrational distrust of others, such as suspicion that people are taking or hiding things.
- **Hallucinations:** Seeing, hearing, or feeling things that are not there.

Other LBD Symptoms

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

- Problems with blood pressure
- Difficulty regulating body temperature
- Dizziness
- Fainting
- Frequent falls
- Constipation
- Urinary incontinence
- Sensitivity to heat and cold
- Sexual dysfunction
- Poor sense of smell

Diagnosis

It's important for people with the symptoms of LBD to get an accurate diagnosis, both to tailor treatment to particular symptoms and to understand what to expect with the disease. It may take more than one visit with a clinician to diagnose a person with LBD.

LBD includes two related diagnoses — dementia with Lewy bodies and Parkinson's disease dementia.

Dementia With Lewy Bodies

People with **dementia with Lewy bodies** have a decline in their thinking ability, especially in the areas of attention, visual perception, and executive function. Over time, they will also develop other distinctive symptoms that distinguish this form of dementia from others. These may include:

- Visual hallucinations early in the course of dementia
- Fluctuations in cognitive ability, attention, and alertness
- Slowness of movement, tremor, difficulty walking, or rigidity (parkinsonism)
- REM sleep behavior disorder, in which people appear to physically act out their dreams by yelling, flailing, punching, kicking, and falling out of bed
- More trouble with complex mental activities — such as multitasking and problem solving — than with memory.

Dementia with Lewy bodies is often hard to diagnose because its early symptoms may resemble those of Alzheimer's or a psychiatric illness. As a result, it is often misdiagnosed or missed altogether. As additional symptoms appear, it is often easier to make an accurate diagnosis.

Parkinson's Disease Dementia

Another form of LBD is known as **Parkinson's disease dementia.** Some people with Parkinson's disease — a disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination — may experience changes in their cognitive function over time. If this happens more than a year after movement symptoms appear, then Parkinson's disease dementia may be diagnosed.

Not all people with Parkinson's disease develop dementia, and it is difficult to predict who will, though this is an area of active research. Being diagnosed with Parkinson's later in life is a risk factor for Parkinson's disease dementia.

People with either form of LBD eventually develop similar symptoms due to the presence of Lewy bodies in the brain. But there are some differences. For example, the symptoms of dementia with Lewy bodies may worsen more quickly than those of Parkinson's disease dementia.

The Importance of a Diagnosis

Receiving an accurate diagnosis may be a long process, but the good news is that doctors are increasingly able to diagnose both forms of LBD earlier and more accurately as researchers identify which symptoms help distinguish them from similar disorders.

Difficult as it is, getting an accurate diagnosis of LBD early on is important so that a person:

- Can get the right medical care and avoid potentially harmful treatment
- Has time to plan for medical care and arrange legal and financial affairs
- Can build a support team to maximize quality of life
- Can consider enrolling in clinical research to find new ways to diagnose, treat, and manage LBD

Having a diagnosis of LBD is also important for the person's caregivers and for others who care about and support them. Not only does it allow them to better understand and prepare for what will happen with the disease, it also enables them to plan for how to take care of themselves throughout the process.

While a diagnosis of LBD can be distressing, some people are relieved to know the reason for their troubling symptoms. It is important to allow time to adjust to the news. Talking about a diagnosis can help shift the focus toward developing a care plan.

JIM'S STORY

Jim, a 60-year-old executive assistant, began having trouble managing the accounting, paperwork, and other responsibilities of his job. He became increasingly irritable, and his daughter insisted he see a doctor. Jim was diagnosed with depression. He was prescribed an antidepressant, but his thinking and concentration problems worsened. When he could no longer function at work, his doctor diagnosed him with Alzheimer's. A few months later, Jim developed a tremor in his right hand. He was referred to a neurologist, who finally diagnosed him with dementia with Lewy bodies. Having this diagnosis helped Jim and his daughter plan for the next steps in his treatment and care.

Who Can Diagnose LBD?

Many physicians and other medical professionals are unfamiliar with LBD, so patients may consult several doctors before receiving a diagnosis. Visiting a primary care doctor is often the first step for people who are experiencing changes in thinking, movement, or behavior.

Primary care doctors may refer patients to neurologists — doctors who specialize in disorders of the brain and nervous system — who generally have the expertise needed to diagnose LBD. For specialty care in diagnosing and managing LBD, both cognitive and behavioral neurologists and movement disorder neurologists have specific training to diagnose and support a person with LBD. Geriatric psychiatrists, neuropsychologists, and geriatricians may also be skilled in diagnosing the condition.

If you can't find a specialist in your community, ask the neurology department of the nearest medical school for a referral. Hospitals affiliated with a medical school may also have dementia or movement disorders clinics that can provide expert evaluation.

Tests Used to Diagnose LBD

Doctors perform physical and neurological examinations and various tests to distinguish LBD from other illnesses. An evaluation may include:

- **Medical history and physical examination:** A review of previous and current illnesses, medications, and current symptoms and tests of movement and memory give the doctor valuable information.
- **Medical tests:** Laboratory analysis of blood samples and other tests can help rule out other diseases, hormonal problems, and vitamin deficiencies that can be associated with cognitive changes. Undergoing a sleep study can help diagnose and identify sleep disorders, which can be treatable.
- **Brain imaging:** Different types of brain imaging — such as CT scans and MRIs, along with certain types of PET (positron emission tomography) scans, can detect brain shrinkage and structural abnormalities and can help rule out other possible causes of dementia or movement symptoms.
- **Neuropsychological tests:** These tests are used to assess memory and other cognitive functions and can help identify affected brain regions.

No single brain scan or medical test can definitively diagnose LBD. Currently, LBD can be diagnosed with certainty only by a brain autopsy after death. However, the development of new diagnostic tests is an ongoing priority.

Researchers are studying ways to diagnose LBD more accurately while patients are living. For example, biomarker testing is being evaluated in research studies to help make a diagnosis. Additionally, certain types of brain imaging — PET scans and single-photon emission computed tomography — have shown promise in detecting differences between dementia with Lewy bodies and Alzheimer's. These methods may help diagnose certain features of the disorder, such as dopamine deficiencies, and to rule out other conditions.

Other tests measure proteins associated with LBD using a lumbar puncture (spinal tap) or skin biopsies to help distinguish LBD from Alzheimer's and other brain disorders.

Talking With Your Doctor

It is important for the person seeking a diagnosis and their care partners to tell the doctor about:

- Any symptoms involving thinking and memory
- Changes or concerns with movement, sleep, behavior, or mood
- Other health problems
- All medications and supplements that the person is currently taking, including prescriptions, over-the-counter drugs, vitamins, and supplements. Certain medications can worsen LBD symptoms, so it is important to pay attention to responses to medications as well.

Patients and their care partners should bring up any concerns they have with the doctor. The more information a doctor has, the more accurate a diagnosis can be.

Treatment and Management

While 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 important.

People with LBD may benefit from physical therapy and exercise. Talk with your doctor about what physical activities are best. A skilled care team often can suggest ways to 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 specialists in dementia and/or movement disorders. Good places to find an LBD specialist include a dementia or movement disorders clinic in an academic medical center or a specialty practice group in your community. If you cannot find an LBD specialist in your area, a general neurologist should be part of the care team. Ask a primary care physician for a referral.

Doctors often work with other types of health care providers as part of a care team. Depending on an individual's particular symptoms, these professionals may 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 voice volume, voice projection, and swallowing difficulties.
- **Occupational therapists** can help with 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 or mental health conditions and plan for the future.

Finding Support

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.

The following organizations provide free assistance to people with LBD and their care partners and can help you find a support group:

- **AARP**
  www.aarp.org/caregiving
  877-333-5885
- **Caregiver Action Network**
  www.caregiveraction.org
  202-454-3970
- **Family Caregiver Alliance**
  www.caregiver.org
  800-445-8106
- **Lewy Body Dementia Association**
  www.lbda.org
  800-539-9767
- **Lewy Body Dementia Resource Center**
  https://lewybodyresourcecenter.org
  516-218-2026 or 833-LBD-LINE

Palliative Care and Planning Ahead

The goal of palliative care is to improve a person's quality of life by providing comfort and relieving disease symptoms at any stage of illness. Palliative care can help manage LBD symptoms such as constipation, sleep disorders, and behavioral changes. Typically, a team of nurses, social workers, physical therapists, dieticians, and pharmacists work with doctors to:

- Relieve troubling symptoms
- Assist with medical decisions
- Offer emotional and spiritual support
- Coordinate care

To find a palliative medicine specialist, ask a physician or local hospital for a referral or consult CaringInfo, a service of the National Hospice and Palliative Care Organization. Visit **www.caringinfo.org**. For more information on palliative care, visit **www.nia.nih.gov/faqs-palliative-care**.

Planning now for your future health care can help ensure you get the medical care you want and that someone you trust will be there to make decisions for you. PREPARE For Your Care, funded in part by the National Institute on Aging, is an interactive online program that helps you fill out an advance directive and express your wishes in writing. Explore the tool at **https://prepareforyourcare.org**. For more information on advance care planning, visit **www.nia.nih.gov/health/advance-care-planning**.

Medications for Common Symptoms

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 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. See page 25 for more information.

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, to treat cognitive symptoms in Parkinson's disease dementia. This and other Alzheimer's drugs can have side effects such as nausea, diarrhea, and dizziness.

KAMAR'S STORY

Kamar was an executive with a background in designing and testing aircraft engines. When he retired at age 67, his wife Manjit noticed that he had problems with complex mental activities. He also had trouble with tasks that required him to complete multiple steps in order. His doctor prescribed a medication for the cognitive symptoms, which helped. His wife credits the medication for helping Kamar have a better quality of life.

Movement Symptoms

LBD-related movement symptoms may be treated with a Parkinson's medication called levodopa. This drug can help improve functioning by making it easier for the person to walk, get out of bed, and move around. However, it can't 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 not recommend treating mild movement symptoms with medication. If prescribed, 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.

Sleep Disorders

Sleep problems may increase confusion and behavioral changes in people with LBD, and they can be difficult for caregivers to manage as well. A physician can order a sleep study to identify underlying sleep disorders such as sleep apnea, restless leg syndrome, or REM sleep behavior disorder. People with REM sleep behavior disorder and their bed partners may be at risk of sleep-related injuries.

BRUCE'S STORY

Bruce started having bad nightmares in his late 60s. Later he had problems communicating and would sit for long periods of time staring out the window. By age 73, Bruce's sleep problems had worsened. While he was asleep, he talked, his limbs jerked, and he thought his dreams were real. Upon waking, he thought he had been at work or out with friends. Medications helped both Bruce and his wife get more rest.

Clonazepam, a drug used to control seizures and relieve panic attacks, is often effective for REM sleep behavior 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 and other sleep problems (like sleep apnea) have been ruled out or treated, a sleep specialist may prescribe a stimulant to help the person stay awake during the day.

Some people with LBD have insomnia. If insomnia 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. The 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 at night. Avoiding alcohol, caffeine, or chocolate late in the day can help, too. Some over-the-counter medications commonly used for pain can also affect sleep or can worsen daytime memory and alertness, so review all medications and supplements with a physician.

Behavioral and Mood Changes

Behavioral and mood changes in people with LBD can arise from hallucinations or delusions, pain, illness, stress or anxiety, feeling overwhelmed, or the inability to express frustration and fear. As a result, the person may resist care or lash out verbally or physically.

Caregivers can use a variety of strategies to handle such challenging behaviors. Some behavioral changes can be managed by making changes to the person's environment and/or treating medical conditions. Other changes may require medication. Caregivers may not recognize their own stress and should consider taking care of their own mental and physical health to better help their loved one. Respite care, which provides short-term relief for primary caregivers, can be a good option.

Sometimes, a medical condition unrelated to LBD can cause behavioral and mood symptoms. Injuries, fever, urinary tract or pulmonary infections, pressure ulcers (bedsores), and constipation can worsen behavioral changes and increase confusion. Talk to a doctor if these symptoms suddenly worsen.

Certain medications used to treat LBD symptoms or other diseases may also cause behavioral changes. For example, some sleep aids, pain medications, bladder control medications, antihistamines, 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 the person's medications regularly with their doctor to determine if any changes are needed.

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, often work well in people with LBD.

Not all behavioral changes are caused by illness or medication. A person's surroundings — including levels of stimulation or stress, lighting, daily routines, and relationships — can contribute to behavior issues. Making changes to the home environment can help minimize anxiety and stress for the person with LBD.

Coping With Behavioral Changes

Working with a physician, people with LBD and their care partners can follow these steps to address behavioral changes:

- Rule out physical causes, like infection, pain, or other medical conditions.
- Review current prescription and over-the-counter medications, as well as any vitamins and supplements.
- Look for environmental or social factors that may be contributing to behavioral changes.
- Consider treating behavior changes with medication, if necessary, and watch for side effects.

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, Delusions, and Other Psychiatric Symptoms

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 person's concerns or fears instead of arguing or responding with facts 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. Another approach that may help can be to redirect attention to something comforting, such as music.

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 after environmental and lifestyle changes are considered. Cholinesterase inhibitors do not affect behavior immediately, so they should be considered part of a long-term strategy.

In some cases, antipsychotic medications, which are used to treat hallucinations, delusions, or agitation, are prescribed to treat LBD-related behavioral symptoms. These types of medications may improve the quality of life and safety of the person with LBD and his or her caregiver but must be used with caution because they can be dangerous for people with LBD. 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. People with LBD should talk with their doctor before reducing or stopping their medication.

Many LBD experts prefer quetiapine or clozapine to control difficult behavioral symptoms. Possible side effects may include sleepiness and low blood pressure. In addition, clozapine has a rare risk of affecting white blood cell counts so it requires regular blood draws for monitoring.

JOHN'S STORY

At 58, John started seeing small children outside the window who were not there. Eventually, he began talking with some of these children, who 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 John's doctor, who said that since the hallucinations were not disruptive, no medication was needed. She advised Linda not to argue with her husband about whether or not the children were there.

Warning About Antipsychotics

People with LBD may have severe reactions to or side effects from antipsychotics. These side effects include increased confusion, worsened parkinsonism, extreme sleepiness, and low blood pressure that can result in dizziness and fainting. Some of the side effects stop when the medication is stopped, but others are permanent. Caregivers should contact a doctor if they notice side effects that continue after a few days.

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.

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

In addition to typical antipsychotics, other antipsychotics, including olanzapine and risperidone, should be avoided, if possible, because they are more likely than others to cause serious side effects.

In rare cases, a person with LBD can have an adverse reaction to antipsychotics, and a potentially deadly disorder called neuroleptic malignant syndrome can occur. This disorder usually starts within the first two weeks of treatment but can also happen at any time during treatment. Symptoms of this disorder include high fever, muscle rigidity, and muscle tissue breakdown that can lead to kidney failure. Report these symptoms to the person's doctor immediately.

Other Treatment Considerations

LBD affects the part of the nervous system that regulates automatic body functions such as blood pressure maintenance 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 and be sure to mention the LBD diagnosis. Constipation can often be treated by exercise and changes in diet, though laxatives, stool softeners, or other treatment may also 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 to develop a plan for careful withdrawal and for resuming medications when appropriate. 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. These changes may take time to subside, and in some cases, can 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 often or in high doses.

Vitamins and Supplements

The use of vitamins and supplements to treat LBD symptoms has not been studied extensively and is not recommended. Some vitamins and supplements can be dangerous when taken with other medicines. People with LBD and their care partners should tell their doctors about every medication they take, including prescription and over-the-counter medicines, vitamins, and supplements.

Advice for People Living With Lewy Body Dementia

Coping with a diagnosis of LBD and all that follows can be challenging. Getting support from family, friends, and professionals is critical to ensuring the best possible quality of life. Creating a safe environment and preparing for the future are important, too. Take time to focus on your strengths, enjoy each day, and make the most of your time with family and friends. Below are some ways to live with LBD day to day.

Getting Help

Your family and close friends are likely aware of changes in your thinking, movement, and behavior. You may want to tell others about your diagnosis so they can better understand the reason for these changes and learn more about LBD. For example, you could say that you have been diagnosed with a brain disorder called Lewy Body Dementia, and it can affect thinking, movement, and behavior. By sharing your diagnosis with those closest to you, you can build a support team to help you manage LBD.

Over time, you will likely have more trouble managing everyday tasks such as taking medication, paying bills, and driving. You will gradually need more assistance from family members, friends, and perhaps professional caregivers. Although you may be reluctant to seek help, try to let others partner with you so you can manage responsibilities together. Remember, LBD affects the people who care about and support you, too. Accepting assistance from them can help reduce stress for everyone involved.

Finding someone you can talk with about your diagnosis — a support group, a trusted friend or family member, a mental health professional, or a spiritual advisor — may be helpful. See the "Resources" section to find support services in your area.

Consider Safety

The changes in thinking and movement that occur with LBD require attention to safety issues. Consider these steps:

- Fill out and carry the LBD Medical Alert Wallet Card (available at **www.lbda.org/lbd-medical-alert-wallet-card**) and present it any time you are hospitalized, require emergency medical care, or meet with your doctors. It contains important information about medication sensitivities.
- Consider subscribing to a medical alert system, in which you push a button on a bracelet or necklace to access emergency services.
- Address safety issues in your home, including areas of fall risk, including rooms with poor lighting, stairs, and cluttered walkways. Think about home modifications that may be helpful, such as installing grab bars in the bathroom or modifying stairs and adding ramps. Ask your doctor to refer you to a home health agency for a home safety evaluation.
- Talk with your doctor about LBD and driving, and have your driving skills evaluated, if needed.

Plan for Your Future

There are many ways to plan ahead. Here are some things to consider:

- If you are working, consult with a legal and financial expert about planning for disability leave or retirement. Symptoms of LBD will interfere with work performance over time, and it is essential to plan now to obtain benefits that you are entitled to.
- Consult with an attorney who specializes in elder law or estate planning to help you write or update important documents, such as a living will, health care power of attorney, advance directive, and will. Be sure to keep these documents secure and in an area that your caregiver can access. Other possible sources of legal assistance and referral include state legal aid offices, state bar associations, local nonprofit agencies, foundations, and social service agencies. You can also visit **www.nia.nih.gov/advance-care-planning** for information on how to plan for the future.
- Identify local resources for home care, meals, and other services **before** you need them. The Eldercare Locator can help you find services in your community. Call 800-677-1116 or visit **www.eldercare.acl.gov**.
- Explore moving to a retirement or continuing care community where varying levels of care can be provided over time. Ask about staff members' experience caring for people with LBD.

Find Enjoyment Every Day

Your approach to living with LBD can help you maintain enjoyment in daily life. Despite the many challenges and adjustments, you can continue to have moments of humor, tenderness, and gratitude with the people closest to you.

Make a list of events and activities you can still enjoy — then find a way to do them! For example, you can listen to music, exercise, or go out for a meal with family and friends. If you can't find pleasure in daily life, talk with your doctor or another health care professional about ways to cope. Let your family and friends know if you are struggling emotionally so that they can offer support.

Caring for a Person With Lewy Body Dementia

MARK AND ROBERT'S STORY

Mark realized that his father, Robert, could not manage a lot of stimulation. Robert easily became agitated and confused, so Mark avoided taking him to places with large crowds or noisy environments. Mark found that soothing music calmed Robert when he grew anxious. Establishing a routine with familiar faces in smaller groups has allowed Robert to enjoy a better quality of life with dementia with Lewy bodies.

As someone caring for a person with LBD, you will take on many different responsibilities over time. You do not have to face these responsibilities alone. Many sources of help are available, from adult day centers and respite care to online and in-person support groups.

Below are some actions you can take to adjust to your new role, be realistic about your situation, and care for yourself. See the "Resources" section for more information.

Educate Others About LBD

Most people, including many health care professionals, are not familiar with LBD. For example, emergency room physicians and other hospital workers, as well as staff in long-term care and other facilities, may not know that people with LBD are extremely sensitive to antipsychotic medications. Caregivers can educate health care professionals and others by:

- Informing hospital staff of the LBD diagnosis and medication sensitivities and requesting that the person's neurologist be consulted before giving them any medications to control behavior changes or other LBD-related symptoms.
- Sharing educational pamphlets and other materials with doctors, nurses, and other health care professionals who care for the person with LBD. Materials are available from the National Institutes of Health, the Lewy Body Dementia Association, and others (see the "Resources" section on page 46).
- Teaching family and friends about LBD so they can better understand and provide support.

Prepare for Emergencies

People with LBD may experience sudden declines in functioning or unpredictable behaviors that can result in visits to the emergency room. Infections, pain, or other medical conditions often cause increased confusion or behavioral problems. Caregivers can prepare for emergencies by having available:

- A list of the person's medications and dosages
- A list of the person's health conditions, including allergies to medicines or foods; see the medical alert card at **www.lbda.org/lbd-medical-alert-wallet-card**
- Copies of health insurance card(s)
- Copies of health care advance directives, such as a living will
- Contact information for doctors, family members, and friends

Adjust Expectations

You will likely experience a wide range of emotions as you care for the person with LBD. Sometimes, caregiving will feel loving and rewarding. Other times, it can lead to frustration, impatience, resentment, or fatigue. Recognize your strengths and limitations, especially in light of your past relationship with the person. Roles may change between a husband and wife or between a parent and child. Adjusting expectations can allow you to approach your new roles realistically and to seek help as needed.

People approach challenges at varied paces. Some people want to learn everything possible and be prepared for every scenario, while others prefer to take one day at a time. Caring for someone with LBD requires a balance. On one hand, you should plan for the future. On the other hand, you can make each day count and focus on creating enjoyable and meaningful moments.

Care for Yourself

As a caregiver, you play an essential role in the life of the person with LBD, so it is critical for you to maintain your own health and well-being. You may be at increased risk for poor sleep, depression, or illness as a result of your responsibilities. Watch for signs of physical or emotional fatigue such as irritability, withdrawal from friends and family, and changes in appetite or weight.

All caregivers need time away from caregiving responsibilities to maintain their well-being. Learn to accept help when it's offered and learn to ask family and friends for help. One option is professional respite care, which can be obtained through home care agencies and adult day programs. Similarly, friends or family can come to the home or take the person with LBD on an outing to give you a break.

Supporting Families of People With Lewy Body Dementia

LBD creates significant changes in family routines and relationships. Family members will cope more effectively if the disorder becomes part of, but not all of, their lives. It's important for families to make time for fun. Breaking up challenging times with fun and enjoyment can help make the challenges easier to face.

Address Family Concerns

Not all family members may understand or accept LBD at the same time, and this can create conflict. Some adult children may deny that parents have a problem, while others may be supportive. It can take a while to learn new roles and responsibilities.

DIANE AND JIM'S STORY

Diane's husband Jim was diagnosed with LBD two years ago. Their son and daughter, who live across the country, thought that Diane was making too much of his illness. She arranged a family meeting virtually and asked them to join. A counselor who specializes in geriatric care provided the family with background and educational materials on LBD, and they talked about the kind of emotional support Diane needs. They are on a better road to teamwork now.

Family members who visit occasionally may not fully understand the symptoms that primary caregivers see daily. They may underestimate or minimize the caregiver's responsibilities or stress. Professional counselors can help provide guidance on how families can work together to manage LBD.

Helping Children and Teens Cope With LBD

When someone has LBD, it affects the whole family, including children and grandchildren. Children and teens may feel a change or loss of connection with the person with LBD, particularly if the person has problems with attention or alertness.

Even young children notice when something "doesn't seem right." Telling them in age-appropriate language that someone they know or love has been diagnosed with a brain disorder can help them make sense of the changes they see. Give them enough information to answer questions or provide explanations without overwhelming them.

If a parent is the caregiver for a person with LBD, children may resent receiving less attention and may benefit from special time with that parent. Look for signs of stress in children, such as worsening grades at school, withdrawal from friendships, or unhealthy behaviors at home. Parents may want to notify teachers or counselors of the LBD diagnosis in the family so they can watch for changes in the young person that warrant attention.

Here are some other ways parents can help children and teens adjust to having a family member with LBD:

- Help them keep up with normal activities outside the home, such as sports, clubs, time with friends, and hobbies.
- Suggest ways for kids to engage with the relative with LBD through structured activities, such as playing a game or reading a book.
- Find online resources for older children and teens so they can learn about dementia and LBD. For example, the following NIA article has information on helping family and friends understand dementia: **www.nia.nih/family-understand-alzheimers**.

Although the following organizations are not specific to LBD, their dementia-related resources and networks may be helpful for children and teens:

- **Alzheimer's Association: Kids and Teens**
  800-272-3900
  www.alz.org/help-support/resources/kids-teens
- **Alzheimer's Foundation of America (AFA) Teens**
  866-232-8484
  https://alzfdn.org/young-leaders-of-afa/afa-teens

Research: The Road Ahead

There is a great deal left to learn about LBD. At a basic level, why does alpha-synuclein accumulate into Lewy bodies, and how do Lewy bodies cause the symptoms of LBD? These questions and others are also of increasing interest to the Alzheimer's and Parkinson's disease research communities. LBD represents an important link between these and other brain disorders, and research into one disease often contributes to better understanding of the others.

Many avenues of research focus on improving our understanding of LBD. Some researchers are working to identify the specific differences in the brain between dementia with Lewy bodies and Parkinson's disease dementia. 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 ways to cure and prevent the disorder. Until then, researchers need volunteers with and without LBD to participate in clinical studies.

Join a Clinical Trial or Other Research Study

By participating in research, you can help scientists discover new information to improve the detection and treatment of LBD. People of all different races, ethnicities, genders, and ages are needed for this research.

To find out more about participating in clinical trials and other research studies, talk with a doctor or visit the following websites:

- **Alzheimers.gov**
  Search for clinical trials and studies on Alzheimer's and related dementias, cognitive impairment, brain health, and caregiving.
  www.alzheimers.gov/clinical-trials

- **Alzheimer's Disease Research Centers**
  These NIA-funded centers conduct research and provide resources for people and families with dementia.
  www.nia.nih.gov/health/alzheimers-disease-research-centers

- **ClinicalTrials.gov**
  Search a database of privately and publicly funded clinical studies conducted around the world.
  www.clinicaltrials.gov

- **Lewy Body Dementia Association (LBDA) Research Centers of Excellence**
  Find information on more than 20 academic medical institutions in the United States that conduct research and that people with LBD and their families can turn for advanced LBD diagnosis and treatment.
  www.lbda.org/research/research-centers-of-excellence

- **LBDA Lewy Trial Tracker**
  Sign up to receive information about clinical trials and studies on LBD.
  www.lbda.org/participate-in-research-survey

- **Michael J. Fox Foundation for Parkinson's Research**
  Find information about current clinical trials and studies on Lewy body diseases, particularly Parkinson's disease.
  www.michaeljfox.org/join-study

Resources

Federal Government

National Institute of Neurological Disorders and Stroke
NINDS supports research to advance knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease for all people.
800-352-9424
braininfo@ninds.nih.gov
www.ninds.nih.gov

National Institute on Aging
Alzheimer's and related Dementias Education and Referral (ADEAR) Center
The NIA ADEAR Center offers information and free print publications about Alzheimer's 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.
800-438-4380
adear@nia.nih.gov
www.nia.nih.gov/alzheimers

MedlinePlus
National Library of Medicine
MedlinePlus is an online health information resource for patients and their families and friends.
www.medlineplus.gov

Eldercare Locator
This service of the U.S. Administration on Aging and U.S. Administration for Community Living connects older Americans and their caregivers with trustworthy local support resources.
800-677-1116
eldercarelocator@USAging.org
www.eldercare.acl.gov

Nonprofit Organizations

Family Caregiver Alliance
The Alliance provides information, resources, and support to family caregivers of adults with physical and cognitive impairments, such as Parkinson's disease, stroke, Alzheimer's, and other types of dementia. They also provide a searchable list of caregiver services by state.
800-445-8106
info@caregiver.org
www.caregiver.org

Lewy Body Dementia Association
LBDA provides education and research to support those affected by LBD, their families, and caregivers.
800-539-9767
support@lbda.org
www.lbda.org

Lewy Body Dementia Resource Center
The LBD Resource Center provides information about LBD, community activities, support groups, and listings of LBD clinical specialists, including neurologists and therapists.
833-523-5463 (833-LBDLINE)
norma@lbdny.org
https://lewybodyresourcecenter.org

Parkinson's Foundation
The Parkinson's Foundation supports research and provides information and resources for people living with Parkinson's, their families, and caregivers, including clinical specialists, support groups, and local events.
800-473-4636
helpline@parkinson.org
www.parkinson.org

The National Institute on Aging (NIA) and the National Institute of Neurological Disorders and Stroke (NINDS) are part of the National Institutes of Health, the nation's medical research agency — supporting scientific studies that turn discovery into health.

NIA leads the federal government effort conducting and supporting research on aging and the health and well-being of older people. NIA's Alzheimer's and related Dementias Education and Referral (ADEAR) Center offers information and publications on dementia and caregiving for families, caregivers, and professionals.

NINDS is the nation's leading funder of research on the brain and nervous system. The mission of NINDS is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease for all people.

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