



FACING LBD TOGETHER

Increasing Knowledge
Sharing Experience
Building Hope



An Introduction to Lewy Body Dementia

A special publication for people newly diagnosed with Lewy body dementia and those still seeking answers.

www.lbda.org



The Lewy Body Dementia Association is here to help.

We know the word dementia is very frightening. Simply stated, it means *a decline in mental functions that affects daily living*. With Lewy body dementia (LBD), dementia is the primary symptom but is only one component of the disease. When you live with dementia, you and those around you will have to adapt to your changing abilities. This booklet will help you and your family understand your diagnosis and prepare for the changes ahead.

You don't have to face Lewy body dementia alone.

The Lewy Body Dementia Association (LBDA) is here to inform, assist, and support you and your family as you begin your journey with this form of dementia. Since 2003, LBDA has grown to national recognition as a leader in LBD issues. Our website - www.lbda.org - provides a range of in-depth information on LBD, including:

- Educational resources on LBD
- Medical research updates
- Virtual communities to exchange tips for living with LBD, offer support, or simply lend an ear
- Local and virtual LBD support groups
- Opportunities to participate in LBD research studies

We encourage you to visit www.lbda.org and join with the many people who have successfully found information, resources, and most importantly, connections with others affected by LBD.

Lewy Line:

1-800-LEWYSOS

1-800-539-9767



Understanding Lewy body dementia

Lewy body dementia is not a rare disease. It affects more than a million people and their families in the United States alone. Because LBD symptoms may closely resemble other more commonly known disorders like Alzheimer's disease, it is currently widely under-diagnosed.

LBD is an umbrella term for two related diagnoses. A person with *dementia with Lewy bodies* will develop dementia and other LBD symptoms, one of which may be changes in movement like a tremor. This is called parkinsonism. In the other form of LBD, people will present **first** with changes in movement leading to a Parkinson's disease diagnosis; over time many will develop dementia **years later**. This is diagnosed as "*Parkinson's disease dementia*". Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms. The earliest symptoms of *dementia with Lewy bodies* and *Parkinson's disease dementia* are different, but both are due to the same underlying biological changes in the brain.

LBD is a multi-system disease and usually requires a comprehensive treatment approach with a collaborative team of physicians and other health care professionals like occupational, physical or speech therapists. Early diagnosis and treatment may extend your quality of life and independence. Many people with LBD enjoy significant lifestyle improvement with a comprehensive treatment approach, and some may even experience little change from year to year.

LBD symptoms and treatments

Each person with LBD is different in terms of which symptoms they have in the beginning. The most common symptoms include changes in thinking, behavior, movement, and sleep. Managing these symptoms requires a careful balance. Some people with LBD are extremely sensitive, or may react negatively to certain medications used to treat Alzheimer's or Parkinson's disease. Be sure to discuss any over-the-counter medications you are using with your provider.

- **Dementia** refers to a significant decline in thinking ability. With LBD it affects memory, decision making, problem solving, planning, and abstract or analytical thinking. These symptoms may improve if treated with cholinesterase inhibitors, medications originally developed for Alzheimer's disease.
- **Cognitive fluctuations** involve unpredictable changes in concentration, alertness or attention.
- **Parkinson's-like symptoms** include slowness of movement, rigidity or stiffness, shuffling gait, tremors, and balance problems. Treatment caution is needed to not worsen other symptoms; low doses of a Parkinson's medication called levodopa may be helpful for some people.
- **Sleep disorders** include REM sleep behavior disorder (RBD), excessive daytime sleepiness, temporary loss of consciousness with difficulties waking, insomnia, and restless leg syndrome. These sleep problems can be subtle and hard to diagnose. Evaluation by a sleep specialist can help identify and treat these issues. RBD involves acting out dreams and may result in injuries from hitting bed partners or falling out of bed. Symptoms of RBD may appear years before any of the other symptoms of LBD. The diagnosis of RBD is important because treatment with melatonin and/or clonazepam can be effective.
- **Autonomic symptoms** are common in LBD. The autonomic nervous system controls many involuntary functions. Problems with temperature and blood pressure regulation can occur, as well as constipation, urinary incontinence, and sexual dysfunction. Low blood pressure can cause dizziness and fainting when a person stands from a sitting or lying position too quickly.

- **Behavioral changes** include hallucinations, delusions or changes in mood.

Hallucinations are seeing or hearing things that are not really present and can occur in other senses like hearing, touch and smell. If the hallucinations are not disruptive, they may not need to be treated. However, if they are frightening or create challenging behavioral changes, your physician may recommend treatment. Cholinesterase inhibitors are sometimes effective in treating hallucinations and other psychiatric symptoms of LBD.

In addition, newer 'atypical' antipsychotic medications may be tried. Most LBD experts prefer quetiapine or clozapine when treatment is necessary for safety or quality of life concerns. Caution is required to find the lowest effective dose in this situation. A newer medication, pimavanserin, was approved to treat psychosis in Parkinson's disease; results from another clinical trial of this medication in people with dementia and psychosis are pending.

While older 'traditional' antipsychotic medications such as thiorazine and haloperidol are commonly prescribed for Alzheimer's patients with disruptive behavior, these medications may cause severe side effects in those with LBD. For this reason, older traditional antipsychotic medications like haloperidol should be avoided.

WARNING: Up to 50% of LBD patients treated with any antipsychotic medication may have a severe reaction, such as worsening confusion, heavy sedation, and increased or possibly irreversible parkinsonism. If severe fever or muscle rigidity occurs, contact your doctor immediately; you may have a potentially life-threatening condition that is treated by stopping the medication.

Delusions (false beliefs) and paranoia (unwarranted suspicions) can occur, sometimes alone or in response to threatening hallucinations.

Changes in mood, including depression, anxiety, and apathy, are extremely common in LBD and may significantly affect your quality of life. Your doctor may recommend treating depression with certain classes of antidepressants.



Certain medications may worsen your condition.

Speak with your doctor about all medications you are currently taking, including over-the-counter medications. Some may be causing side effects that worsen LBD symptoms; these may need to be reduced or stopped. The following drugs may cause sedation, motor impairment, or confusion:

- Benzodiazepines, tranquilizers like diazepam and lorazepam
- Anticholinergics (antispasmodics), such as oxybutynin and glycopyrrolate
- Some surgical anesthetics
- Older antidepressants
- Certain over-the-counter medications, including sleep aids and the antihistamines diphenhydramine and dimenhydrinate

Some medications, like anticholinergics, amantadine, and dopamine agonists, which help relieve parkinsonian symptoms, might increase confusion, delusions or hallucinations.


Surgery and anesthesia

Be sure to meet with your anesthesiologist in advance of any surgery to discuss medication sensitivities and risks unique to LBD. People with LBD often respond to certain anesthetics and surgery with acute states of confusion or delirium and may have a sudden significant drop in functional abilities, which may or may not be permanent.

Possible alternatives to general anesthesia include a spinal or regional block. These methods are less likely to result in postoperative confusion. If you are told to stop taking all medications prior to surgery, consult with your doctor to develop a plan for careful withdrawal.

Other types of treatments

- Lifestyle interventions include eating a healthy diet, exercising, and remaining socially active.
- Physical therapy includes cardiovascular, strengthening and flexibility exercises, as well as gait training.
- Speech therapy may improve low voice volume, poor enunciation, muscular strength, and swallowing difficulties.
- Occupational therapy helps maintain skills and promotes functional ability and independence.
- Music and aromatherapy may reduce anxiety and improve mood.
- Individual and family psychotherapy may 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.
- Support groups may be helpful for caregivers and persons with LBD to identify practical solutions to day-to-day frustrations and to obtain emotional support from others.



What is the long-term prognosis for someone with Lewy body dementia?

The prognosis is different for each person and may be affected by your general health or the existence of unrelated illnesses. Because LBD progresses at varying rates for each individual, it is not possible to determine how long someone may live with the disease.

A person may live as long as 20 years or as short as 2 years after onset of obvious LBD symptoms. Research suggests **most people** live five to eight years with LBD. It is important to remember that this is a disorder that progresses gradually over years, not days or months.

Some families must make the decision whether or not to inform a person with LBD about their diagnosis. Those decisions may depend on the cognitive ability and temperament of the individual with LBD. While some people may find a dementia diagnosis distressing, research indicates that most individuals actually find some relief in knowing the diagnosis and in understanding how this relates to their changing abilities. A correct diagnosis can also lead to a tailored treatment plan.



LBD is a family disease

LBD affects both the person with LBD and their entire family, so it is important to be proactive. Here are a few things you can do today to plan ahead.

- Share your diagnosis with those closest to you, so you can stand together to face LBD.
- Become a knowledgeable partner with your doctor. Learn everything you can about LBD symptoms, treatment options, and caregiving. Visit the Lewy Body Dementia Association's website at www.lbda.org to learn more.
- Fill out and carry the *LBD Medical Alert Wallet Card* included in this booklet, and present it any time you are hospitalized, require emergency medical care, or meet with new doctors.
- Assess your home for possible modifications needed to ensure you have a safe living environment.
- Subscribe to a medical alert bracelet service to provide important medical information to emergency care providers.
- Identify local resources that provide information or assistance before you need it, including your local Area Agency on Aging office.
- Consult with an attorney who specializes in elder law about your legal and financial situation during the early stage of LBD. Consider a durable power of attorney for healthcare decisions.
- Contact national organizations including the Administration on Aging, Family Caregiver Alliance or National Alliance for Caregiving for additional information on caregiving.
- Consider participating in a research study to help in the fight against LBD. LBDA Research Centers of Excellence provide both clinical care and opportunities to participate in cutting-edge LBD research. Visit www.LBDA.org/RCOE to learn more.



What if I haven't received a diagnosis yet?

Sometimes early dementia symptoms can be vague, making the type of dementia hard to identify. It may take several years for enough symptoms to develop to point to a specific type of dementia.

Some types of dementia are reversible. They may be caused by an interaction of certain medications, a vitamin deficiency or a curable illness. If you are experiencing changes in your memory or cognitive abilities, please consult with a doctor to identify the cause and begin treatment immediately.

Unfortunately, for many types of dementia, there are no known cures. These types of dementia mainly affect older adults, though some people are diagnosed with 'early-onset dementia' as young as their forties. Getting an early and accurate diagnosis along with appropriate treatment is very important, since people with LBD often respond very differently to certain medications.

Other common types of dementia:

Alzheimer's disease

Alzheimer's disease symptoms include a progressive loss of recent memory; problems with language, calculation, abstract thinking, and judgment; depression or anxiety; personality and behavioral changes; and disorientation to time and place. LBD is frequently misdiagnosed as Alzheimer's disease, especially in the early stage. Over time, changes in movement, hallucinations or RBD can help distinguish LBD from Alzheimer's disease.

Vascular dementia

Vascular dementia is caused by a series of small strokes that deprive the brain of vital oxygen. Symptoms – such as disorientation in familiar locations; walking with rapid, shuffling steps; incontinence; laughing or crying inappropriately; difficulty following instructions; and problems handling money – may appear suddenly and worsen with additional strokes. High blood pressure, cigarette smoking, and high cholesterol are some of the risk factors for stroke that may be controlled to prevent vascular dementia.

Frontotemporal dementia

Frontotemporal dementia (FTD) includes several disorders with a variety of symptoms. The most common signs of FTD include changes in personality and behavior, such as inappropriate or compulsive behavior, euphoria, apathy, decline in personal hygiene, and a lack of awareness concerning these changes. Some forms of FTD involve language and speech symptoms or movement changes.



Do I have to see a special kind of doctor to find out what type of dementia I have?

Primary care providers are a great, first-step resource if you are experiencing any cognitive, emotional, or physical changes. However, neurologists generally possess the specialized knowledge necessary to diagnose specific types of dementia or movement disorders, as do geriatric psychiatrists and neuropsychologists. However, these specialists may require a referral from your primary care provider. Geriatricians, who specialize in treating older adults, are also usually familiar with the different forms of dementia.



LBDA Research Centers of Excellence provide both clinical care and opportunities to participate in cutting-edge LBD research. Visit www.LBDA.org/RCOE to learn more.



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The information on this card is intended for general informational use only. It is not intended to be medical advice or to take the place of competent medical professionals who are familiar with a particular patient's situation. Each individual is advised to make an independent judgment regarding the content and use of this information.

MEDICAL ALERT CARD

I have a disorder of the brain known as **LEWY BODY DEMENTIA (LBD)** which could make me appear confused and have difficulty moving or speaking normally.

Please call my family or my physician!

Thank you to the LBDA Scientific Advisory Council for their medical review in the creation of this card.
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My Name: _____

Address: _____

Person to Call: _____

Address: _____

Phone: _____

Physician: _____

Phone: _____

Allergies: _____

Other Medical Conditions: _____



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Emergency Treatment of Psychosis in LBD

Psychotic symptoms such as visual hallucinations of people or animals or misidentifying one's spouse or one's home are common in LBD. The goal of addressing these symptoms is to ensure the safety of the patient and others.

WARNING

Up to 50% of patients with LBD who are treated with any antipsychotic medication may experience severe neuroleptic sensitivity (worsening cognition, heavy sedation, increased or possibly irreversible parkinsonism, or symptoms resembling neuroleptic malignant syndrome, which can be fatal).

- 1. Identify possible etiologies of delirium, e.g., pain, infection, metabolic stress, alcohol withdrawal.
- 2. Reduce or eliminate anticholinergic medications, such as over-the-counter sleep agents and bladder-control medications, and reduce dopaminergic drugs used to treat Parkinson's disease, if clinically indicated.
- 3. Consult with a doctor experienced in treating LBD. Cholinesterase inhibitor drugs may improve cognition and psychiatric symptoms, although such effects are not usually immediate.

- 4. Antipsychotic agents may be indicated if psychotic symptoms are severe and pose a significant safety risk. **AVOID traditional antipsychotic agents (e.g., haloperidol).** Newer atypical antipsychotic agents (e.g., quetiapine, clozapine) should only be used with caution at the lowest dose possible, under close supervision of a physician and a registered nurse (RN), and should be switched to a safer medication as soon as possible.

A more comprehensive physician's guide to treating behavioral disturbances in LBD patients can be found at www.lbda.org/go/ER

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By supporting the work of LBDA,
you too will be

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To learn more about LBD, visit www.lbda.org

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