An Introduction to Lewy Body Dementia

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

You don't have to face LBD alone.

Lewy Body Dementia Association, Inc.

Increasing Knowledge
Sharing Experience
Building Hope

www.lbda.org

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You don't have to face Lewy body dementia alone. The Lewy Body Dementia Association is here to educate, assist, and support you and your family as you begin your journey with this unique form of dementia. Since 2003, LBDA has grown to national recognition as a leader in LBD issues. You will find more in-depth information on our website, www.lbda.org, including:

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LBD Caregiver Link:

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1-800-539-9767

Understanding Lewy Body Dementia

Lewy body dementia is not a rare disease. It affects an estimated 1.3 million individuals and their families in the United States alone. Because LBD symptoms may closely resemble other more commonly known diseases like Alzheimer's and Parkinson's, it is currently widely under-diagnosed.

LBD is an umbrella term for two related diagnoses. It refers to both 'Parkinson's disease dementia' and 'dementia with Lewy bodies.' The earliest symptoms differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms.

LBD is a multi-system disease and usually requires a comprehensive treatment approach with a collaborative team of physicians from varying specialties. 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.

Some people with LBD are extremely sensitive, or may react negatively, to certain medications used to treat Alzheimer's or Parkinson's disease, as well as certain over-the-counter medications.

LBD symptoms and treatments:

- **Dementia** is the primary symptom and includes problems with memory, problem solving, planning, and abstract or analytical thinking. Cholinesterase inhibitors, medications originally developed for Alzheimer's, are the standard treatment today for cognitive LBD symptoms.
- **Cognitive fluctuations** involve unpredictable changes in concentration and attention from day to day.
- **Parkinson's-like symptoms** include rigidity or stiffness, shuffling gait, tremor and slowness of movement. Sometimes a Parkinson's medication called levodopa is prescribed for these symptoms.
- **Hallucinations** are seeing or hearing things that are not really present. If the hallucinations are not disruptive, they may not need to be treated further. However, if they are frightening or dangerous, your physician may recommend a cautious trial use of a newer antipsychotic medication. (Please see WARNING below.) Dementia medications called cholinesterase inhibitors have also been shown to be effective in treating hallucinations and other psychiatric symptoms of LBD.
- **REM sleep behavior disorder** (RBD) involves acting out dreams, sometimes violently. This symptom appears in some people years before any changes in cognition. Some sleep partners have reported being physically injured when the disorder was left untreated. RBD can be responsive to treatment by melatonin and/or clonazepam.

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

- **Severe sensitivity to neuroleptics** is common in LBD. Neuroleptics, also known as antipsychotics, are medications used to treat hallucinations or other serious mental disorders. While traditional antipsychotic medications, e.g., haloperidol and thioridazine HCL are commonly prescribed for individuals with Alzheimer's for disruptive behavior, these medications can affect the brain of an individual with LBD differently, sometimes causing severe side effects. For this reason, **traditional antipsychotic medications like haloperidol should be avoided**. Some newer 'atypical' antipsychotic medications like risperidone may also be problematic for someone with LBD. Some LBD experts prefer quetiapine. If quetiapine is not tolerated or is not helpful, clozapine should be considered, but requires ongoing blood tests to assure a rare but serious blood condition does not develop. Hallucinations must be treated very conservatively, using the lowest doses possible under careful observation for side effects.

Other common Lewy body dementia symptoms not required for diagnosis:

These symptoms also need to be monitored and treated:

- Significant changes in the autonomic nervous system, including temperature regulation, blood pressure and digestion. Dizziness, fainting, sensitivity to heat and cold, sexual dysfunction, early urinary incontinence, or constipation are common LBD symptoms.
- Repeated falls attributed to dizziness, fainting, or the effects of parkinsonism on posture and balance.
- Excessive daytime sleepiness or transient loss of consciousness. Sleep disorders are common in LBD, but are often undiagnosed. If you experience these symptoms, consult with a sleep specialist to identify and treat all sleep disorders.
- Other mood disorders and psychiatric symptoms such as depression, delusions (false beliefs), or hallucinations in other senses, like touch or smell. Your doctor may recommend treating depression with classes of antidepressants called SSRIs or SNRIs.

Certain medications may worsen your condition.

Speak with your doctor about possible side effects. 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 diphenhydramine and dimenhydrinate

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

NOTE: 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.

Not all treatments include taking medications:

- Physical therapy includes cardiovascular, strengthening, flexibility exercises, gait training, and general physical fitness programs.
- 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.

The average duration of LBD is typically five to eight years after the onset of obvious LBD symptoms, but may range from two to twenty years. 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 the 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, a recent study 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 an optimum treatment plan.

What if I Haven't Received a Diagnosis Yet?

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

Some types of dementia are reversible and 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 so you can 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 early as their forties. Getting an early and accurate diagnosis along with appropriate treatment is very important, since people often respond very differently to certain medications.

Other common types of dementia:

- Alzheimer's disease patients experience 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.
- 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 (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?

Family physicians 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 physician. Geriatricians, who specialize in treating older adults, are also usually familiar with the different forms of dementia. If you have access to a hospital affiliated with a medical school, the hospital may have a clinic specializing in dementia or movement disorders where you may find a high level of diagnostic and treatment capability.

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LBD is a family disease, affecting both the patient and primary caregiver.

Unfortunately, LBD is not an easy disease with which to live. It affects both the person with LBD and their entire family. Here are a few things you can do today to start preparing for the challenges 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 your doctors.
- 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.
- Contact national organizations including the Administration on Aging, Family Caregiver Alliance or National Alliance for Caregiving for additional information on caregiving.

Please detach and fill out this Emergency Medical Information Card. Present it every time you are hospitalized, in the emergency room, or meeting a physician for the first time.

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Thank you to the **LBDA Scientific Advisory Council** for their medical review in the creation of this card.
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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!

My Name:_____
Address:_____
_____
Person to Call:_____
Address:_____
_____
Phone:_____
Physician:_____
Phone:_____
Allergies:_____
Other Medical
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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 OTC 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 an 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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