

What can you do?

There are several ways you can help raise awareness about LBD.

- Join us as a volunteer
- Make a donation today
- Talk to friends and family about LBD
- Join or start a support group
- Give these brochures to your healthcare provider

About the LBDA

Whether you've been recently diagnosed, you're a caregiver, a healthcare professional, or are just looking for more information – we're here for you.

The **Lewy Body Dementia Association** is an organization created by LBD affected families and caregivers. Our goal is simple:

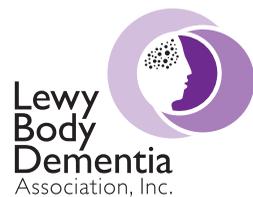
Increasing Knowledge

Sharing Experience

Building Hope

Through our website and outreach programs we provide:

- LBD clinical and caregiving information
- A national support group network
- LBD discussion forums
- LBD event calendar
- Printed and multimedia educational resources
- The Lewy Body Digest, LBDA's e-newsletter



Visit us online at:

www.lbda.org

Phone: 404-935-6444

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Facts About LBD Lewy Body Dementias

LBD
Lewy Body
Disease

DLB
Dementia with
Lewy Bodies

PDD
Parkinson's Disease
Dementia

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up to the minute information.



Facts about LBD

Lewy body dementia or LBD [which includes the clinical diagnoses of *dementia with Lewy bodies* (DLB) and *Parkinson's disease dementia* (PDD)] is a progressive brain disease and the second leading cause of degenerative dementia in the elderly.

- LBD affects an estimated 1.3 million individuals and their families in the US.
- Nearly 80 percent of LBD caregivers report that LBD is not the initial diagnosis.
- LBD is most frequently misdiagnosed as Alzheimer's disease.

Early Diagnosis is Important

In the primary care setting (and even in many specialty settings) physicians regularly do not recognize the distinguishing symptoms of LBD, as LBD-identifying symptoms are hidden among common symptoms shared with more familiar diseases, like Alzheimer's disease (AD) and/or Parkinson's disease (PD).

Early diagnosis and treatment are extremely important because it:

- Identifies the risk of extreme sensitivity to neuroleptics (medicines used to treat hallucinations) and provides the maximum opportunity to avoid (or at least minimize) exposure
- Provides early treatment opportunities with cholinesterase inhibitors (medicines used for dementia) which may maximize the patient's independence and quality of life
- Allows for the detection and treatment of sleep disorders, resulting in optimum cognition with adequate rest
- Allows families to make plans for the future in accordance with the patient's preferences

More Research is Needed

Research into early diagnosis, imaging and cognitive testing, mechanisms of disease, and better forms of treatment is important. Consider asking about and participating in research studies.

Diagnosis

An experienced clinician within the medical community should perform a diagnostic evaluation. If one is not available, the Neurology or Psychiatry department of the nearest medical school should be able to recommend appropriate resources or may even provide an experienced diagnostic team skilled in Lewy body dementia.

A thorough dementia diagnostic evaluation includes physical and neurological examinations, patient and family interviews (including a detailed lifestyle and medical history), and neuro-psychological and mental status tests. The patient's functional ability, attention, language, visuospatial skills, memory and executive functioning are assessed. In addition, brain imaging (CT or MRI scans), blood tests and other laboratory studies may be performed. The evaluation should provide a clinical diagnosis, though for some patients it can take a year or more for enough symptoms to develop to accurately identify LBD.

Currently, a conclusive diagnosis of LBD can be obtained only from a postmortem autopsy for which arrangements should be made in advance. Some research studies may offer brain autopsies as part of their protocols.

Risk Factors

Advanced age is considered to be the greatest risk factor for Lewy body dementia, with onset typically but not always, between the ages of 50 and 85. Some cases have been reported much earlier. LBD appears to affect slightly more men than women. Having a family member with LBD may increase a person's risk but LBD is not normally considered an inherited disease. Risk factors include Parkinson's disease (PD) and possibly REM Sleep Behavior Disorder (RBD).

Observational studies suggest that adopting a healthy lifestyle (exercise, mental stimulation, nutrition) might delay age-associated dementias. Studies have also shown that risk factors for dementia in general include: excessive alcohol intake; smoking; repeated head injury or trauma; high blood pressure; diabetes; open heart surgery; long term extreme stress; high cholesterol; sedentary lifestyle (lack of blood flow to the brain); and lower education (lower brain stimulation).

Primary LBD Symptoms

The symptoms of Lewy body dementia vary from person to person, and can mimic other diseases, especially in the early years. As a result, it is not uncommon for people with LBD to be diagnosed with Alzheimer's, Parkinson's, or similar brain diseases. The latest clinical diagnostic criteria for LBD groups symptoms into three types:

Central Feature:

Dementia - a progressive cognitive decline that features executive functioning deficits, like the inability to plan or perform abstract or analytical thinking.

Core Features:

Fluctuating cognition with clear variations in attention, alertness and wakefulness. This fluctuation may make it difficult to accurately evaluate and test the person on a single visit.

Recurrent visual hallucinations that are typically well formed and detailed. These are usually present early in the course of the illness.

Parkinsonism usually occurs at the same time or after the onset of dementia in LBD patients, and precedes the other symptoms by several years in Parkinson's disease dementia patients. (See right for further details.)

Suggestive Features:

REM sleep behavior disorder (RBD) includes vivid dreaming, talking in sleep, purposeful and sometimes violent movements, falling out of bed, and can lead to injuries. Sometimes only the patient's bed partner is aware of these symptoms. RBD often precedes cognitive and other LBD symptoms by many years.

Severe sensitivity to certain neuroleptics (medications used to treat psychiatric symptoms).

Abnormal result on SPECT or PET scans of brain function, which are often only performed at specialized clinics.

A clinical diagnosis of LBD can be "probable" or "possible" based on different symptom combinations:

A probable LBD diagnosis requires either:

- Dementia plus two or more core features, or
- Dementia plus one core feature and one or more suggestive features.

A possible LBD diagnosis requires:

- Dementia and one core feature, or
- Dementia and one or more suggestive features.

Other LBD Symptoms

Supportive Features: (These are commonly present and can support an LBD diagnosis when they occur with 'core' or 'suggestive' features.)

- Repeated falls, fainting, myoclonus (sudden muscle jerks or twitches)
- Hallucinations of sound, touch, smell, taste
- Transient/unexplained unresponsiveness
- Autonomic problems: fainting or dizziness on standing due to low blood pressure; constipation, unexplained sweating or coldness
- Urinary problems (incontinence), sexual difficulties
- Delusions (false beliefs), delusional misidentification
- Anger, sadness, depression
- Difficulty swallowing, choking, weak voice

Alzheimer's-like (cognitive) symptoms:

- Progressive memory loss
- Depression, changes in mood, behavior
- Decreased judgment, loss of initiative
- Disorientation regarding time and place
- Difficulty with language and tasks

Parkinsonian (motor) symptoms:

- Muscle stiffness and rigidity
- Very slow movements, frozen stance
- Balance difficulties, shuffling gait
- Tremor
- Loss of dexterity

Parkinsonian (motor) symptoms (continued):

- Small handwriting
- Stooped posture (pronounced leaning, generally to one side or forward)
- Blank facial expression

Other possible symptoms:

- Excessive daytime sleepiness
- Abnormal depth perception, directional sense, object orientation, illusions
- Restless leg syndrome (RLS)

Treatments

An accurate diagnosis is needed to guide treatment. Medical management of Lewy body dementia is complex because of increased sensitivity to many drugs. Some medications prescribed for Alzheimer's and Parkinson's symptoms can adversely affect people with LBD. Even LBD-experienced doctors often have difficulty finding tolerable and effective treatments for movement disorder symptoms and persistent hallucinations. All prescription and over-the-counter drugs should be initiated at the lowest effective dose and managed by an LBD-experienced physician (e.g., a neurologist or neuropsychiatrist).

Clinically proven medications for LBD:

- Cholinesterase inhibitors (AD medications): Improve alertness and cognition; potentially reduce hallucinations & behavioral symptoms
- Drugs for parkinsonian symptoms may benefit some people. (See PD drug side effects.)

Treatments observed to benefit some people:

- Some antidepressants may lessen depression and anxiety, and improve sleep. (See "Warning")
- Antiepileptic drugs may reduce anxiety, agitation. (Potential side effects, use with caution.)
- Some antipsychotic drugs (neuroleptics) may reduce agitation and severe hallucinations, aggression, or delusional beliefs. (See "Warning")
- Physical therapy, massage, exercise, redirection techniques, music, aromatherapy.

Warning:

Up to 50% of patients with LBD who are treated with traditional antipsychotic medications (neuroleptics) may experience worsening cognition, heavy sedation, increased or possibly irreversible parkinsonism, or symptoms resembling neuroleptic malignant syndrome that can be fatal.

Some drugs with possible adverse side effects:

- Benzodiazepines, anticholinergics, some surgical anesthetics, antidepressants and some over-the-counter medications may cause sedation, motor impairment or confusion.
- Some medicines useful for Parkinsonian symptoms, including anticholinergics, amantadine and dopamine agonists, may increase confusion, delusions or hallucinations.
- When considering any surgery, caregivers should meet with the anesthesiologist in advance. People with LBD often respond to certain anesthetics and surgery with acute confusional states (delirium) and/or may have a precipitous drop in functional abilities which may or may not be permanent. The pros and cons of stopping donepezil, rivastigmine, or galantamine should be carefully considered. If a spinal block or regional block can be used instead of general anesthesia, this would be preferred as those methods are less likely to result in postoperative confusion.

(Although every attempt is made to ensure the information contained within is timely and accurate, the providers of this information cannot be held responsible for any errors or omissions. This pamphlet is not intended to be medical advice, and information concerning medical care or the suitability or use of any medication should be discussed with a medical doctor.)

Prognosis

Although Lewy body dementia is progressive, the rate of progression varies greatly, allowing no way to predict the course of the disease for any given individual. The disease has an average duration of 5 to 7 years from the time of diagnosis, but progression can vary widely from 2 to 20 years. Age and general health are important determinants of longevity in the setting of any neurodegenerative disease.