

Lewy Body Dementia (LBD): A Guide for Patients & Families

Lewy Body Dementia (LBD) is a progressive brain disorder caused by abnormal protein deposits called Lewy bodies in the brain. These deposits affect thinking, movement, sleep, and behavior. LBD shares features with both Alzheimer's disease and Parkinson's disease and is one of the most common causes of dementia in older adults.

Signs & Symptoms to Watch For

Common Cognitive Symptoms

- Fluctuating attention and alertness
- Difficulty with problem solving or complex tasks
- Visuospatial problems (difficulty judging distance or navigating spaces)
- Memory may be relatively preserved early compared with Alzheimer's disease

Behavioral & Neurologic Changes

- Visual hallucinations (seeing people, animals, or objects that are not present)
- Parkinsonian symptoms such as tremor, stiffness, or slowed movement
- Sleep disturbances, especially REM sleep behavior disorder (acting out dreams)
- Depression, anxiety, or apathy
- Increased sensitivity to certain medications, especially antipsychotics

Typical Presentation & Progression

Early Stage

- Fluctuating thinking and alertness
- Visual hallucinations
- Sleep disturbances
- Mild movement changes

Middle Stage

- Increasing cognitive impairment
- Worsening movement symptoms
- More frequent hallucinations or behavioral symptoms
- Need for assistance with daily activities

Late Stage

- Severe cognitive impairment
- Significant movement problems
- Difficulty swallowing or walking
- Full dependence for daily care

Medications FDA-Approved for Cognitive Symptoms

Symptom-Targeted Medications

- Rivastigmine (Exelon®) — FDA-approved for Parkinson's disease dementia and commonly used in Lewy body dementia
- Donepezil (Aricept®) — may help cognitive symptoms and hallucinations in some patients
- Galantamine (Razadyne®) — sometimes used for cognitive symptoms

Medications Used for Movement or Behavioral Symptoms

- Carbidopa/levodopa — may help stiffness and slowed movement
- Melatonin or clonazepam — sometimes used for REM sleep behavior disorder
- Antipsychotics must be used with extreme caution due to severe sensitivity in many LBD patients

Diagnostic Tests Your Healthcare Team May Use

Clinical & Cognitive Evaluation

- Detailed medical history and symptom review
- Cognitive screening such as the Montreal Cognitive Assessment (MoCA)
- Neurological examination assessing movement and reflexes

Laboratory Tests

- Blood tests to rule out other causes of cognitive symptoms
- Thyroid testing, vitamin deficiencies, and metabolic evaluation

Imaging Studies

- MRI or CT scans — rule out stroke, tumor, or structural causes
- Dopamine transporter (DaT) scan — may help support diagnosis in select cases

Planning for the Future

Healthcare Planning

- Discuss goals of care early while the person can express preferences.
- Establish advance directives and healthcare power of attorney.
- Consider specialty dementia care as symptoms progress.

Legal & Financial Planning

- Assign durable financial power of attorney.
- Review insurance coverage and long-term care planning.
- Consult elder-law professionals when appropriate.

Support for Caregivers

- Hallucinations and fluctuating symptoms can be stressful for families.
- Establish routines and seek respite support when possible.
- Caregiver education and support groups can be very helpful.

National Organizations & Resources

✓ Lewy Body Dementia Association (LBDA)

☎ 800-539-9767 | 🌐 lbda.org — education, caregiver resources, and support groups.

✓ Alzheimer's Association 24/7 Helpline

☎ 800-272-3900 | 🌐 alz.org — dementia support and care resources.

✓ National Institute on Aging (NIA)

☎ 800-438-4380 | 🌐 nia.nih.gov — research and educational resources.

✓ Eldercare Locator

☎ 1-800-677-1116 | 🌐 eldercare.acl.gov — connects families with local aging services.

Final Notes

- Lewy Body Dementia often involves a combination of cognitive, movement, and sleep symptoms.
- Early recognition can help guide treatment and safety planning.
- Caregiver support is essential because symptoms can fluctuate and be unpredictable.