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Lewy Body Dementia

By

Edward F. Ansello, PhD

Dementia isn't a specific disease in itself but a term that describes a set of **symptoms** that can reflect many different and sometimes overlapping conditions or causes. Dementia includes progressive impairments in memory and recognition, changes in personality, and losses in reasoning ability and self-care that interfere with daily life. Dementia is the result of brain disease or injury from such causes as Alzheimer's disease, Dementia with Lewy Bodies (DLB), vascular dementia, frontotemporal lobe dementia, or Traumatic Brain Injury (TBI).

So, while Alzheimer's disease is the most common and widely known cause of dementia, it is not the only cause. Dementia with Lewy Bodies (DLB), in fact, may be the second most common cause of progressive dementia but it is certainly less well known.

Alzheimer's and DLB have similar causes in that each is the result of inappropriate deposits of protein in the brain, called neurofibrillary tangles and amyloid Beta plaques in Alzheimer's and called Lewy bodies in DLB, named after Dr. Frederich Lewy. Lewy discovered the abnormalities in how the brain processes the protein alpha-synuclein while working in Dr. Alzheimer's laboratory in the early 1900s.

It turns out that these Lewy bodies are found in the brains of people who have Alzheimer's disease or have Parkinson's disease. It's the relationship between DLB and Parkinson's that is significant: some who have Parkinson's eventually develop dementia and some people with DLB eventually develop Parkinson's symptoms; the latter include various problems with movement, like muscle rigidity, shuffling gait, and bent posture, and clinically are called parkinsonisms.

A family caregiver or health care provider may notice behaviors in the person under consideration. Common early symptoms in Alzheimer's include difficulty remembering recent conversations, names, and events; apathy, depression; perhaps loss of smell. Common early symptoms with DLB may be similar to Alzheimer's but with sleep disturbances, hallucinations, and parkinsonianisms. The movement problems are hallmarks of DLB, "core clinical features."

Recently, I participated in a fine webinar hosted by the federal Health Resources and Services Administration (HRSA) which featured Angela Taylor, Director of Programs at the Lewy Body Dementia Association. I am indebted to her for much of the following information.

DLB affects men more than women, with age of onset being anywhere from 50 to 85.

Cognitive or brain processing problems with DLB are somewhat similar to those with Alzheimer's and include forgetfulness, trouble with problem solving or analytical thinking; difficulty planning or keeping track of sequences; disorganized speech and conversation; difficulty with sense of direction or spatial relationships between objects.

Someone with DLB often has fluctuations in concentration, alertness, episodes of confusion, and excessive daytime sleepiness. Also, as mentioned, parkinsonisms are characteristic of DLB, including rigidity or stiffness, a shuffling walk, balance problems or falls, tremors, slowness of movement, decreased facial expression, and a change in posture.

While hallucinations and delusions are more symptomatic of delirium than of dementia, individuals with DLB tend to have these, as well as a heightened sensitivity to antipsychotic medications that may be used initially to treat these symptoms. So these medications can be dangerous in people with DLB.

Sleep disorders are common. A person with DLB may act out dreams, sometimes striking or otherwise injuring a bed partner. Insomnia and restless leg syndrome are common. Again the connection of DLB to movement disorders.

Lastly, there are distinctive autonomic dysfunctions, meaning involuntary or unconscious actions, such as dizziness or fainting, difficulties with regulating body temperature, urinary incontinence, constipation, and unexplained blackouts or transient loss of consciousness.

All of these symptoms present great challenges to family caregivers. More so because there's so little public awareness of DLB. Caregiver burden occurs early and may be higher than in Alzheimer's disease because of the disparate symptoms and the reality that clinicians may be late in diagnosing what may seem like an odd and diverse set of symptoms.

Things are not hopeless, however. If the individual with DLB is diagnosed early, he or she often is more responsive to interventions than with a diagnosis later in the progression of the disease. Persons with DLB have been found to be more responsive to cholinesterase inhibitors, the types of drugs usually prescribed for those with Alzheimer's. Medications for controlling parkinsonisms like dopamine promoters may help. But treatment is a balancing act; medications for one symptom can worsen another.

Caregivers need to be alert, therefore, for medication sensitivities, including the need to minimize the use of neuroleptics/antipsychotics, which are powerful tranquilizers prescribed to reduce confusion, delusions, and hallucinations; specifically, avoid older antipsychotics like haloperidol. In someone with DLB, these drugs may worsen the individual's cognition or behavior, producing apathy or limiting movement, just what's not desired in someone with DLB.

The Lewy Body Dementia Association (LBDA) endorses a comprehensive treatment plan, one that includes appropriate medications for the person with DLB, a regimen of physical exercise, alertness to medication sensitivities and adverse drug effects, and a focused attempt to improve the quality of life for both the person with LBD and the family caregiver. LBDA offers a robust array of information and resources designed to increase the caregiver's understanding of the disease.

LBDA recommends as the current treatment strategy the goal of improving quality of life. It states that many symptoms can be managed or reduced with medications, as well as with nonpharmacological treatments. Because there's such a strong movement disorder component of

DLB, it recommends that the individual participate in occupational therapy (OT), physical therapy (PT), and speech therapy. Again, caregiver education and support are critical.

If you are caring for someone who has been diagnosed with LBD or if you suspect that someone you know may have LBD, visit the association's website at LBDA.org.

The LBDA.org website features tabs on Support groups; LBD Caregiver Link; Publications; Information about LBD for the general public; Support resources for LBD families, including local and virtual support groups, phone and email support; LBD stories written by LBD families; Educational resources, such as webinars for LBD families and healthcare professionals; Research news, including notices of clinical studies that are now recruiting participants; and other ways to get involved with LBDA.