

5 TIPS for caregivers

LEWY BODY DEMENTIA

When you hear “memory impairment,” you probably think of Alzheimer’s or dementia, but there are actually many variations under the dementia umbrella. We often only hear these terms because many of the variations are so hard to diagnose! Lewy Body dementia is one of these that is often overlooked. It is actually the second most common form of degenerative dementia, and widely underdiagnosed with its similarities to both Alzheimer’s disease and Parkinson’s. Though it can be hard to pin down, we’ll count down 5 things to know about Lewy Body dementia.

1 5 typical symptoms.

One of the things that make Lewy Body dementia so hard to diagnose is that the progression is much less predictable. While all diseases vary depending on the individual – their general health and presence of other illnesses – LBD symptoms often appear in varying combinations and severity, making each case unique. Though there isn’t a common progression, there are typical symptoms. **Fluctuations in cognition** are common with LBD; at times the person will seem alert, and then suddenly have confusion lasting hours or days. It is not the same as “sundowning” seen with Alzheimer’s disease, which tends to happen at a specific time of day. **Hallucinations** are also common with LBD, often visual, but can also include sound, taste, smell, and touch. **Parkinson’s symptoms** are also seen (hence the confusing diagnosis), including shuffling gait, body stiffness, or tremors. **REM Sleep Behavior Disorder (RBD)** is often noted in individuals with LBD. During periods of REM sleep, the person may move, gesture, or speak, and there may be more confusion between dreams and waking reality. Finally, **sensitivity to neuroleptic (anti-psychotic) drugs** is often seen with LBD. These drugs can actually worsen all of the other symptoms associated with LBD. These are all considered core or suggestive features of the disease. Others may experience repeated falls and fainting, unexplained loss of consciousness, autonomic dysfunction (problems with blood pressure, heart rate, sweating or digesting food), visuospatial abnormalities (trouble with spatial relationships) or other psychiatric disturbances – these are all supportive features of the disease.

2 What are the drugs for?

The last symptom is especially important to be aware of, as anti-psychotics are often prescribed for Alzheimer’s disease, but can be harmful for those with LBD. Many of these medications are prescribed for behavioral symptoms of Alzheimer’s disease. However, since LBD affects the brain differently, these medications can cause a severe worsening of movement, decrease in cognition, and/or an increase in hallucinations. Additionally, they can lead to a potentially fatal condition known as neuroleptic malignant syndrome (NMS) which causes severe fever, muscle rigidity, and a breakdown leading to kidney failure. So it goes without saying that a proper diagnosis is especially important in this case, to ensure that any drugs prescribed are done so for the right reasons.

LBD symptoms often appear in varying combinations and severity, making each case unique.

3 3 common presentations.

So the symptoms seem fairly straightforward; what makes Lewy Body dementia so hard to diagnose? It often disguises itself as Alzheimer’s disease or Parkinson’s disease! As mentioned, there is no common path of progression, and symptoms often appear in varying

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combinations. There are actually three “typical” ways Lewy Body may present itself – and they’re all very different! The first looks like Alzheimer’s disease. Individuals will start out with memory or cognitive problems, but over time will exhibit the other characteristic symptoms of the disease - fluctuations in cognition, hallucinations, changes in gait, sleep disorders, or sensitivity to anti-psychotics. The second way LBD may present itself looks more like Parkinson’s disease. Symptoms first appear as a movement disorder, and later develop into dementia and the other common symptoms of LBD. Finally, the third group will first present with neuropsychiatric symptoms, such as hallucinations, behavioral problems, or difficult with complex mental activities. This group is most likely to receive an initial diagnosis of Lewy Body dementia, as the disease looks different from its cousins, Alzheimer’s and Parkinson’s.

4 Probable diagnosis = Dementia + 2

We know it’s hard to diagnose, which is why LBD diagnoses are either “probable” or “possible,” depending on how many symptoms are presenting. Just like with a cold – you may mainly have a runny nose, but you could possibly have a sore throat, cough, or watery eyes – not everyone with LBD exhibits all symptoms. Someone with LBD could exhibit memory problems, movement problems, and sleep problems, but never hallucinate. The current diagnostic criteria require that a person have dementia plus two of the common symptoms of LBD. Since we still cannot be completely sure until an autopsy, this is considered a probable diagnosis. If someone has dementia with one of the common symptoms, they would be given a possible diagnosis of LBD.

5 How can you really tell which one?

As a caregiver, does it really make a difference? Will my caregiving approach look different with a diagnosis of LBD versus Alzheimer’s? Yes and no! There are many similarities between Alzheimer’s and Lewy Body dementia, and they will present many similar caregiving needs for the individual’s affected. However, if you’re caring for someone you’re close with, such as a spouse or parent, you may be most likely to notice the subtle differences. For example, while both display cognitive deficits, individuals with LBD often have greater difficulty with executive functioning, such as problem solving, abstract thinking and reasoning, while those with Alzheimer’s disease exhibit decline in memory. You may first notice deficits in Alzheimer’s disease when your mom forgets the grandkids names, but with LBD you may first notice a bounced check from errors in balancing the checkbook. Hallucinations do occur later in Alzheimer’s disease, but are generally much earlier in LBD. If you’re noticing that mom is talking to someone not there without much other memory loss, it might point to LBD. Finally, sleep disorders are not typically seen with Alzheimer’s. The individual may lose their sense of time (and ability to distinguish night and day), but would not exhibit the disorder symptoms such as moving or talking in their sleep. Many of these symptoms are hard to distinguish, which is why it is always important to talk to your doctor with any concerns you may have. Getting a proper diagnosis of LBD can help both you and your loved one in achieving the best quality of life.



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Need more information? Check out the Lewy Body Dementia Association at LBDA.org.