

# WHY YOU NEED TO KNOW ABOUT LEWY BODY DEMENTIA

**More than 1.4 million Americans have Lewy body dementia (LBD) and more than 11 million worldwide, numbers that are probably low, according to Norma Loeb, founder and executive director of the Lewy Body Resource Center.**

“More people have LBD than ALS, muscular dystrophy and cerebral palsy combined, yet LBD is not commonly known. One reason LBD research has lagged that of Alzheimer’s and Parkinson’s for decades is due to an earlier notion that it was a rare disease. It is not rare,” she says.

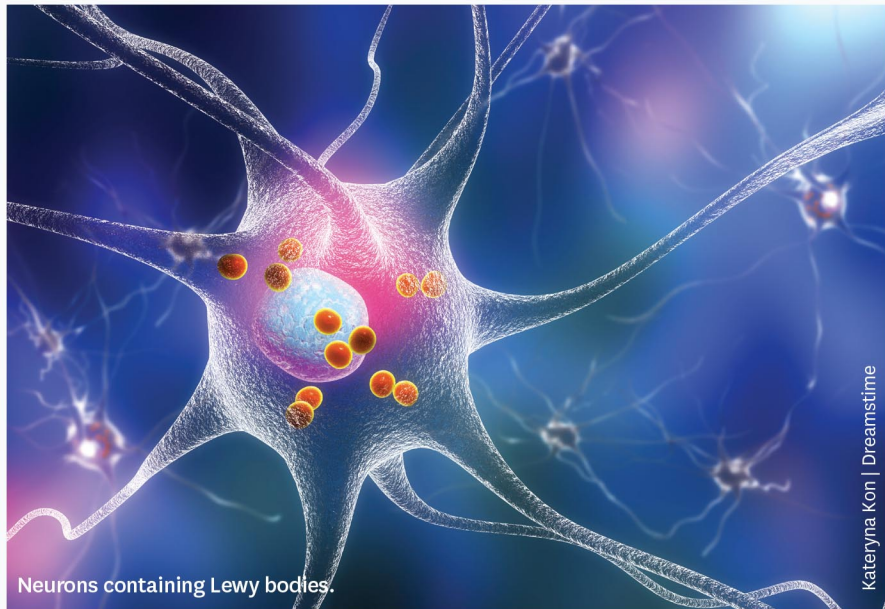
Lewy body is a degenerative neurological dementia, the second most common form after Alzheimer’s. It’s difficult to diagnose because a variety of symptoms present over time. Symptoms overlap with Parkinson’s disease as well as Alzheimer’s. One person with Lewy body dementia is not the same as another person with LBD.

In the brain tissue of people with this condition, there is an aggregation of misshapen protein particles, called alpha-synuclein deposits. These are known as Lewy bodies.

Dr. Fritz Jacob Heinrich Lewy discovered these clumps of abnormal proteins in the nerve cells of brains in 1912. However, the first case of LBD wasn’t described until 1961, with the first set of clinical criteria put forth in 1996.

Famous people who have had LBD include Robin Williams, Tom Seaver, Estelle Getty and Casey Kasem. Ted Turner is currently living with it. Health journalist Max Lugavere chronicles the difficult search for answers with his mother, Kathy Lugavere, in his new film *Little Empty Boxes* (see pp. 19-20 for our Q&A).

“Too many people are misdiagnosed and many people who are diagnosed with Alzheimer’s also have Lewy body,” says Loeb, who has been leading LBD support groups for 15 years. “More than 40 percent, for sure, have both, we believe.”



Loeb says key identifiers of LBD can include:

- **Cognition issues:** trouble with multi-tasking and problem-solving more than memory issues, which come later. Many people have a slower time retrieving words in conversation and need more time to respond.
- **Fluctuations** in cognition and awareness.
- **Parkinsonism:** slowness of movement, shuffling walk, rigidity, balance issues. About 80 percent of people with LBD have Parkinson’s. Many people don’t have tremors, but rather slowness of movement, trouble getting out of a chair and balance problems resulting in falls.
- **Hallucinations and delusions:** seeing and hearing things that aren’t there in nearly 80 percent of people living with LBD. They occur early in the condition and typically are realistic and detailed, often involving small animals and children. Delusions involve making up stories that aren’t true, such as a spouse having an affair.
- **REM Sleep Behavior Disorder:** physically acting out dreams, flailing, hitting bed partners. “When we’re sleeping, our bodies are generally frozen. If we’re dreaming of throwing a ball or running, we’re not moving our arms or legs. With someone who has REM Sleep Behavior Disorder, they physically act out their dreams. They can hit the person they’re sleeping with, knock over a lamp and fall out of bed. This can be a very early sign. It can have started 10 years before the other symptoms.”
- **Visuospatial and depth perception problems:** reaching out for a glass and missing or walking into the wall next to the door. “People often say they need to go to an eye doctor, but the problem isn’t in their vision.”
- **Sensitivity to medications** such as those that treat psychosis or are used for anesthesia. “The wrong medications can make symptoms much worse.”

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“If you don’t remember most of these, please remember fluctuations. Somebody with Lewy body can be having a regular conversation and then later that day or the next can barely answer a simple question. That can go on for a few hours or a couple of days.”

### Other symptoms:

**Depression.** “If someone has had depression or anxiety in their lives then it will be worse if they have Lewy body,” Loeb says, adding that even if they’ve never had depression most people with LBD develop it.

**Anxiety.** This is triggered if they are trying to think of something to do, and they are unable and can’t figure out why.

**Apathy.** “They cannot get up the oomph to get up and do anything.”

**Incontinence and constipation.** “In conjunction with everything else, these can be an early sign.”

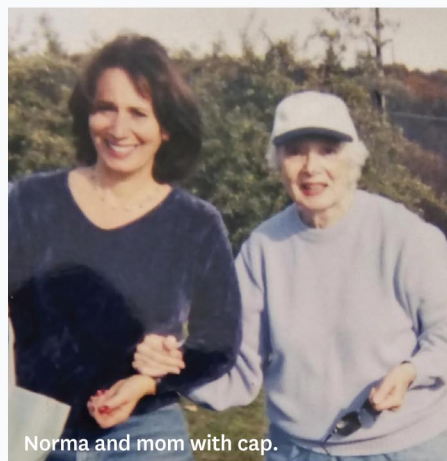
**Orthostatic hypotension (when blood pressure drops suddenly).** This often happens when someone gets up too quickly and can result in falls.

### Why is it important to diagnose LBD correctly?

Like Alzheimer’s and Parkinson’s, LBD has no cure, but it is different because of the sensitivity to medications it brings.

“It’s extremely important that someone is diagnosed correctly because of this. Many people have told me a physician told them because there aren’t any cures for these conditions, it’s not important to describe them. That is not so,” Loeb says.

She suggests a care partner keep a list of all symptoms their loved one has and take it as a history for the doctor.



Norma and mom with cap.

Loeb’s involvement with LBD began after her mother, Lillian, at 75, started having trouble with her checkbook. She took her to an internist who said that was a normal part of aging.

She was referred to a gerontologist who diagnosed her mother with Alzheimer’s,

although he couldn’t understand why her cognition was so sharp. After two years with that misdiagnosis, the doctor said he wanted to watch her mother walk because he thought she might have Parkinson’s.

“I said she’s been walking like that for the two years I’ve been bringing her here. I was then told to take her to a neurologist. That continued for three-and-half years.”

Eventually, Loeb took her mother to a doctor at Mount Sinai Hospital in New York who mentioned Lewy body.

“When I went home, I looked online, and she had almost every symptom there was.”

After her mother passed away eight years ago, Loeb founded the Lewy Body Resource Center with the mission to raise crucially needed awareness and support.

**The Lewy Body Dementia Resource Center ([lbdny.org](http://lbdny.org))** provides support groups and help in seven languages. It also offers a national helpline at **516-218-2026** or **833-LBD-Line** from 8 a.m. to 8 p.m. Norma Loeb invites questions at [norma@lbdny.org](mailto:norma@lbdny.org).

This article is adapted from AFA’s Care Connection webinar “Lewy What? What is Lewy Body Dementia and How Do You, Healthcare Professionals and Caregivers, Deal with It?”

Seeing the brain differently makes a world of difference



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