

Health

Lewy body, the ‘other’ dementia

Questions to ask when a loved one receives a diagnosis of dementia

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When Alissa’s father was diagnosed with dementia after exhibiting cognitive, behavioral and physical impairment, his family assumed it was Alzheimer’s disease, the most common form of dementia. It was only when he ended up in the hospital, with severe psychiatric symptoms and a frightening reaction to medication, that the family received another diagnosis: What Alissa’s father actually had, the doctors informed them, was Lewy body dementia.

The second-most common form of dementia, Lewy body dementia (LBD) affects an estimated 1.3 million Americans, but few people have heard of it. Caused by an abnormal buildup

of deposits (Lewy bodies) in the brain, LBD is closely related to Parkinson’s disease and is often accompanied by problems with gait and movement.

Like Alzheimer’s disease, LBD is progressive and irreversible, with palliative treatment and medications for symptom management recommended to help people maximize quality of life. But there are differences between the two illnesses, including which medications should be prescribed. For people with LBD, traditional antipsychotics should be avoided, as should a number of other medications, according to the Lewy Body Dementia Association (LBDA).

Alissa’s father was originally prescribed a medication contraindicated for LBD, which caused him great psychiatric distress. “If my Dad had been correctly diagnosed, he wouldn’t have displayed such nightmare behavior or been hospitalized – which caused all of us a great deal of concern and stress,” says Alissa.

Unfortunately, there are no specific diagnostic screens—no definitive brain imaging or blood tests—for dementia and its associated illnesses, such as Alzheimer’s or LBD. Rather, doctors make a clinical diagnosis based on medical history, a physical examination, lab tests that might suggest one diagnosis or another, and a finding of marked changes in cognitive and behavioral function. Once you or a loved one receive such a life-changing diagnosis, you should seek referral to a specialist to learn more about what to expect day to day and in the long run, and what the latest treatments are (as well as what to avoid), says Dr. Ritchell Dignam, Medical Director for VNSNY Hospice and Palliative Care. Because LBD overlaps many specialties, she recommends visiting a neurologist, psychiatrist, geriatric specialist and/or movement specialist.

Three Differences

While both forms of dementia are characterized by signifi-

cant cognitive and behavioral decline, there are three key areas of difference between the presentation of Lewy body dementia and Alzheimer’s.

Fluctuations in Cognitive Ability

With LBD, a person’s alertness and attention can fluctuate quickly, often leaving family members confused and alarmed. “You could be having a discussion with them, but then sounds become unintelligible,” says Dr. Samuel Weisblatt, a VNSNY Hospice Team physician. “Fifteen seconds later, they’ll have no recollection that they were unintelligible.”

People with Alzheimer’s, on the other hand, tend to experience a more steady cognitive and functional decline.

Difficulties with Movement and Gait

Much more so than with Alzheimer’s, patients with LBD often show a physical decline from the beginning of their illness that grows more pronounced over time. This may include difficulty walking,

frequent falling, stiffness and tremors (resembling Parkinsonian movements). Physical therapy may help people with LBD, notes Dr. Dignam.

With Alzheimer’s, movement and gait disorders typically present very late in the trajectory of the illness, if at all.

Hallucinations

People with LBD, even in early stages, often have vivid hallucinations. Alissa’s father saw animals—a horse, dog, and cat—and could describe in great detail what they were doing. Such vivid hallucinations are not a typical symptom of Alzheimer’s, although they may appear in late stages of the illness.

For more differences and similarities, see this LBDO reference chart.

Coping Day to Day

Despite these distinctions, what the two dementias have in common—a progressive and profound loss of the ability to remember, think, and perform

Continued on page 10

Lewy body, the ‘other’ dementia

From page 8

daily activities—outweighs their differences. Behavioral health nurses offer the following advice for caregivers dealing with any type of dementia, no matter the diagnosis. The goal with all of these approaches is to keep your loved one safe and comfortable, manage his or her symptoms, and keep yourself, the caregiver, healthy.

Repeat, Repeat, Repeat. “Know that they are going to ask the same questions over and over,” says behavioral health nurse Joel Genaw, who works with people with all types of dementia. “Try to keep them oriented, but you also need to be prepared to be patient about answering and explaining again and again.”

Keep Calm and Carry on — Always keep your tone and facial expressions calm, no matter the crisis. This is not easy. While you would be forgiven for getting agitated the hundredth time you explained something or the twentieth time you attempted help with showering, a visible rise in your stress quickly magnifies your loved one’s stress and makes the situation much worse. Caregivers can learn over time what increases their loved one’s agitation—including unfamiliar surroundings—and try to minimize those situations.

Join hem in their Reality — This is especially helpful when caring for someone with LBD. Remember that their hallucinations are exquisitely real to them, brought on by the physical changes in their brain. While you don’t see the hors-

es running through the fields or their mother sitting on the couch in the living room, never try to convince the person otherwise. Be patient and let them tell their story.

Don’t Take it Personally — It can be upsetting to see and live with such profound changes in your loved one, who might lash out at you in frustration or anger. But remember that it is the disease causing the personality changes. As an organization of professional caregivers, we know how difficult and how incredibly important caregiving is, and we extend thanks to family members and other informal caregivers whenever we have the chance. We also recommend connecting to caregiver support resources, because you cannot give care to others if you don’t take care of yourself.

Through all stages of the illness, it can be helpful for caregivers to be able to manage expectations. And when it comes to the especially challenging task of caring for a loved one with dementia, knowing what to expect can be aided—at least a little—by having the right diagnosis.

For Alissa’s family, the deterioration of their beloved father and husband was heartbreaking. But once they received the diagnosis of Lewy body dementia, they found a small measure of comfort in knowing they were taking the right steps. “We could see him decline before our eyes,” she said. “But once we understood exactly what it was, we had a better idea what was going to happen next. That helped.”