Lewy Who?: Understanding Lewy body dementia

Lewy body dementia (LBD) is likely the most common type of dementia that you have never heard about. It is estimated that there are 1.4 million people living with LBD in the United States, making it the second most common cause of progressive dementia after Alzheimer’s disease. Lewy body dementia is characterized by the presence of clumps of misfolded alpha synuclein proteins, or Lewy bodies, in the cells of the brain. These ‘Lewy bodies’ are named after the neurologist, Dr. Fredrich Lewy, who discovered them.

What is Lewy body dementia?

Lewy body dementia is an umbrella term for two related clinical diagnoses: dementia with Lewy bodies (DLB) and Parkinson’s disease dementia (PDD). These disorders share the same underlying changes in the brain and clinical symptoms, but the symptoms appear in a different order depending on where the Lewy bodies first form.
What is Dementia with Lewy bodies (DLB)?

Dementia with Lewy bodies (DLB) is a type of dementia that causes problems with thinking abilities that are severe enough to interfere with everyday activities. It specifically affects a person’s ability to plan and solve problems, called executive function, and their ability to understand visual information. Attention may also be impacted early in the disease course. In DLB, dementia must be present for diagnosis and must present either first or within one year of the onset of the movement changes, or parkinsonism. The motor symptoms such as rest tremor, slowness, stiffness and walking/balance problems may worsen or become more evident as the disease progresses. Visual hallucinations, REM sleep behavior disorder, fluctuating levels of alertness and attention, mood changes and autonomic dysfunction are also features of DLB (but it is important to state that not everyone will present the same or have all of these features).

What is Parkinson’s disease dementia (PDD)?

In contrast, Parkinson’s disease dementia (PDD) is a term used for dementia that develops after many years of living with Parkinson’s disease (more than one year after the onset of parkinsonism). In those diagnosed with Parkinson’s, the presenting feature is the motor symptoms (parkinsonism) and it is not until years later (more than one year) that changes in cognition may occur- though some may have very mild changes in cognition at the time of diagnosis. Over time, non-motor symptoms of Parkinson’s may increase, including cognitive impairment, REM sleep disorder, fatigue, anxiety, autonomic dysfunction, pain and more. Most importantly, not all people with Parkinson’s disease will develop dementia.

Questions? We can help. Call our Lewy Line for support 1.800.539.9767 or visit our website at lbda.org