

Seeing Lewy Body Dementia From Many Perspectives

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Two common sayings when it comes to dementia are as follows:

- When you have met one person living with dementia, you have met one person.
- If it looks like a duck and quacks like a duck, it's most likely a duck.

While both have elements of truth in them, both also can inspire much misunderstanding of the experience of living with dementia. This has never been more true than when coping with the condition called Lewy Body Disease (LBD). If we believe that each person is absolutely unique and different, then we can fall into the trap of thinking that *they* are the problem. *That person is acting weird. That person is not trying; they can do it when they want to. That person is being paranoid or delusional and ignoring the facts.* When we approach LBD in this way, there is blame assigned, and therefore there is no value in digging deeper into what is causing this escalation or change, or more importantly, in changing our approach and abilities.

On the other hand, if we are only thinking of dementia as some variation of Alzheimers, then Lewy Body Disease will not look much at all like *that* condition for many individuals. It may only show itself as a *memory problem* condition in the later stages or stressful moments. In these situations, it is quite common for the changes in the following areas of the brain to result in an assumption that medications are needed to manage the symptoms. Unfortunately, when drugs are prescribed that are commonly used to manage what is thought to be a mental health condition, there is a very high risk of worsening in overall abilities, unintended side-effects, paradoxical reactions, hypersensitivity, and toxicity resulting in death. Some of the medications of concern are anti-anxiety medications, sleep medications, and anti-psychotic medications. The primary changes seen in LBD are related to a build-up of abnormal alpha-synuclein proteins in a variety of areas in the brain. It is believed that the presence of these accumulations is what causes the on/off symptoms as well as the progressive nature of the condition. If you look at the list below, none of these observed changes would typically make you think of Alzheimers.

These are areas where LBD can cause varying changes:

- core survival functions (low arousal states combined with hyper-alert levels, disturbed wake-sleep patterns with episodes of insomnia and nighttime distress, blood pressure fluctuations)
- visual perception (visual misinterpretations, seeing things others do not, depth and distance problems, loss of 3D versus 2D awareness)
- sensory processing (loss of smell, taste, or hypersensitivity to touch, movement, light, and sound)

- motor control (intention tremors, episodes of rigidity, unexplained fall episodes, difficulty swallowing or chewing)
- thinking (delusions, confabulation, paranoia, anxiety, hopelessness, loss of sequencing skills)

So on one hand a misidentification of LBD as some other mental health condition causes problems, but so does the misinterpretation of changing movement patterns. The symptoms of Parkinsons can hide the presence of LBD or the LBD symptoms can be misidentified as due to Parkinsons. If medications are used to treat tremors and rigidity, and the person also has LBD, the hallucinations, sleep problems, and thinking problems can escalate.

So what should we do? I believe it is valuable to develop a combination of skills and approaches. It helps to be curious, non-judgmental, and supportive. If we do not work hard to gain awareness, knowledge, and skill to develop competence in recognizing and responding to fluctuating symptoms that are not part of Alzheimers or Parkinsons then we miss what is most valuable for the person living with LBD. We must become strong and vocal advocates. If we do not know how to provide the supportive behaviors and environments that are a better match for observed changes in function, interests, language, and interactions as they occur, then we will be part of the problem and will contribute to the person's sense of loss, isolation, and distress. More importantly, we also miss opportunities for seeing the person as valuable, whole, and talented.

To better address LBD, I believe it is essential that we recognize indications that things are changing, and based on our observations, provide the support and care that matches the person's in-the-moment experience. In LBD, flexibility in expectations and approach are critical. One hallmark of this form of dementia is its high degree of variability from moment to moment, day to night, day-to-day, and over time. The range of abilities, over the course of a week, within one person is remarkable and cannot be predicted from what has immediately proceeded. In LBD there are commonly experienced symptoms and patterns, however, many are misunderstood and missed entirely as symptoms of this condition. Missing LBDs signals and signs frequently results in non-management or mismanagement of the condition. The person frequently experiences a sense of isolation, fear and anxiety, premature loss of relationships, disengagement from roles, and missed opportunities.

In this month's journal you will find several perspectives on this condition and hear from several people living with the condition in one way or another.