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The Difference in Lewy Body Dementia

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There are many conditions that cause dementia, Alzheimer's disease being the most prevalent of them, accounting for nearly 70% of cases. Other dementia-causing conditions include Vascular Dementia, Frontotemporal Dementia and Lewy Body Dementia (LBD).

Among cases brought up by caregivers seeking assistance from the Alzheimer's Association, the large number of dementia patients who are misdiagnosed or under-diagnosed is both shocking and alarming. Dementia is a serious condition, often a symptom of a serious disease, and requires thorough examination by a neurologic specialist. Some doctors, not being specialists, fail to provide patients with a dementia diagnosis preferring to call it "senile memory loss," or other even more innocuous, dismissive terms. Others simply clump all cases under Alzheimer's and start treatment as such, without ever referring to a specialist for a proper evaluation.

Each dementia case has its cause and each cause has different symptoms and expected outcomes. Accordingly, each case requires a customized treatment. Ignoring this fact can result in tragic consequences.

Attention to an accurate diagnosis is particularly important in LBD cases. LBD symptoms are inconsistent and fluctuating, therefore difficult to capture during a single consultation in a doctor's office. The Mini-Mental State Examination, a standard test most commonly used in clinical settings to detect dementia, is inadequate to distinguish LBD from other forms of dementia.

Treatment must be administered with extreme caution because LBD patients are highly susceptible to some pharmaceuticals. And considering the complexity of LBD symptoms, as well as their severity and uniqueness, expert medical attention is actually *essential*. In 2014, beloved actor and comedian Robin Williams committed suicide. Upon autopsy it was



discovered that he had been incorrectly diagnosed with Parkinson's disease prior to his death; Williams had LBD. He had also been suffering from depression, anxiety, and increasing paranoia – all possible symptoms of LBD.

LBD was first identified in the early 1900s by Dr. Friedrich H. Lewy, a neurologist who worked with renowned Dr. Alois Alzheimer. Lewy found abnormal proteins in an area of the brain stem where they deplete dopamine, resulting in Parkinson's-like symptoms. These proteins were then named Lewy bodies after the doctor. In LBD patients, Lewy bodies disseminate to other areas of the brain, causing dementia.

Today LBD is an umbrella term for two related diagnoses, referring both to Parkinson's disease dementia and dementia with Lewy bodies. To distinguish between the two diseases clinicians use the one-year rule: if dementia begins within one year of Parkinsonism, it is diagnosed as dementia with Lewy bodies; if later, Parkinson's disease dementia is the diagnosis.

It is estimated that 80 percent of Parkinson's patients will eventually develop dementia. Although the initial symptoms of dementia with Lewy bodies and Parkinson's disease dementia are different, both diseases exhibit the same underlying Lewy bodies-related changes in the brain. Over time, both diseases will exhibit



Tips

REMEMBER:

Diagnosing dementia is a difficult task, requiring experience and expertise. Get a second opinion.

LBD SYMPTOMS

ALWAYS:

Progressive dementia: decline in thinking abilities that interferes with everyday life.

LIKELY:

Planning or problem-solving abilities decline.

Difficulty with sense of direction or spatial relationships between objects.

Fluctuating cognitive abilities, attention or alertness.

Severe sensitivity to medications used to treat hallucinations.

POSSIBLE:

Autonomic dysfunction.

Significant memory loss.

Language problems.

Changes in mood.

Hallucinations.

Delusions and paranoia.

Personality changes.

Depression and/or anxiety.

Changes in walking or movement, such as slower, smaller steps, problems using hands, tremors.

Balance problems and/or falling.

REM sleep behavior disorder.

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similar sleep disturbances and similar cognitive, physical and behavioral symptoms.

SYMPTOMS

Every person with LBD is different and will experience these symptoms to different degrees.

The central feature of LBD is progressive dementia, often accompanied by detailed, complex hallucinations and other psychiatric disturbances (including depression, anxiety, apathy, paranoia and agitation), even at very early stages of the disease. Partners of LBD patients will notice fluctuations in cognition, where one moment the person will be alert and the very next he will have acute episodes of confusion, with no evident trigger. These fluctuations are most perplexing to care partners, who often-times assume that the person is “faking it.”

LBD also presents symptoms similar to Parkinson’s disease, including stiffness in the arms or legs, tremors, changes in gait, shuffling and frequently falling. Although parkinsonian symptoms may also fluctuate, most patients will become non-ambulatory as the disease progresses.

Many patients will be affected by Rapid Eye Movement (REM) Sleep Behavior Disorder, which in some cases may actually be the earliest symptom of LBD, appearing years before the onset of dementia. During REM sleep the person will move, speak and gesture. As the person awakens, there may be a period of confusion between their dreams and reality.

Another key feature of LBD is **extreme sensitivity to neuroleptic (anti-psychotic) drugs**. This is of particular relevance when utilizing pharmacological treatments. Medications used safely and successfully to help patients with other dementias can actually exacerbate LBD’s physical and cognitive symptoms, and intensify hallucinations. They can also cause Neuroleptic Malignant Syndrome, a life-threatening illness characterized by muscle rigidity, fever, delirium and autonomic dysfunction, which includes instability in blood pressure, heart rate, sweating, and digestion. This is the main reason why it is

so important that the patient receives a proper diagnosis and the health care team is well educated about the disease. A treatment based on a misdiagnosis can actually be harmful and potentially fatal.

TREATMENTS

LBD is a complex disease that requires a multi-system treatment approach, including physicians from different specialties. Pharmacological treatments can be used to address the cognitive and psychiatric symptoms, movement symptoms, visual hallucinations and REM Sleep Behavior Disorder.

Always keep in mind that LBD patients are extremely sensitive to medications, including those available over-the-counter, and they may react negatively. Up to 50% of patients with LBD who are treated with antipsychotic medications experience some neuroleptic sensitivity. Speak with your doctor about possible side effects.

Non-pharmacological treatments include physical, speech and occupational therapy. Although these therapies can be helpful in alleviating the severity of symptoms, adherence is a major problem since LBD causes certain behaviors, including apathy and petulance, making compliance unrealistic.

There is no known cure for LBD. Onset of the disease varies between the ages of 50 and 85. The symptomatic phase of the disease has an average duration of 5 to 7 years, although cases lasting up to 20 years have been reported. Studies show that the incidence of LBD is twice as common in men as it is in women.

No one really knows the actual number of LBD cases in the US, in part because LBD diagnoses are often missed and cases can only be confirmed with autopsy. Most experts estimate LBD to be the third most common cause of dementia after Alzheimer’s disease and vascular dementia, accounting for 10 to 25 percent of cases. For more information on LBD, please visit the LBD Association at LBDA.org.



Tools:

LBDA.org - Vast array of information about the disease.

Support Groups - As no patient with dementia has the same experiences as the next, caregivers learn valuable information in support groups regarding how to prepare for and respond to daily challenging dementia symptoms.