

DISCUSSING DIAGNOSIS AND PROGNOSIS OF LBD

Informing the Patient (and Caregiver)

While there is increasing awareness of Lewy body dementia (LBD) among healthcare practitioners, public awareness remains relatively low. The multiple presenting features of LBD may raise suspicion in family members of more widely known disorders such as Alzheimer's disease or Parkinson's disease, or alternatively, a possible psychiatric disorder. As most patients and families will first be introduced to LBD upon initially receiving the diagnosis, providing sound information and shaping appropriate expectations is essential to quality care.

While difficult news to receive, an LBD diagnosis can provide a certain degree of comfort as it helps patients and families make sense of their experiences. Discussion about LBD and its anticipated impact may take place over multiple office visits, due to the complexity of clinical and caregiving matters.

Documenting an LBD diagnosis is imperative, due to severe medication sensitivities and relatively low awareness of LBD outside of specialists. Family caregivers sometimes serve as the first line of defense against administration of traditional neuroleptics in hospitals. It is also critically important to make sure that one or more the core manifestations of LBD is not caused or exacerbated by iatrogenic medications such as neuroleptics or anticholinergic agents.

Prognosis

Like Alzheimer's disease LBD can progress at significantly different rates. The typical prognosis after diagnosing LBD is about 5-7 years, although there is a wide range. Anecdotal experience suggests that the trajectory of LBD progression may mirror the rate of early symptom onset and progression. The prospect of future therapeutic developments that may alter disease progression within this time frame should punctuate any discussion of prognosis.

Progression of LBD¹

There are no formally defined stages of LBD like there are in Alzheimer's disease. Efforts are underway to define the mild cognitive impairment (MCI) stage of LBD to allow for an earlier diagnosis. Until then, expert insights may be useful to both the clinician and LBD family

Early, Suggestive Indicators

- Often recognized only in retrospect, possibly extending back 1-3 years.
- Occasional minor episodes of forgetfulness, sometimes described as lapses of concentration or 'switching off'.

¹ McKeith, I.G., Perry, R.H., Fairbairn, A.F., et al. 1992. Operational criteria for senile dementia of Lewy body type (SDLT). *Psychological Medicine* 22, 911-922.

- An initial brief period of delirium in association with genuine physical illness and/or surgical procedures, return to baseline, followed by a subsequent mental and physical decline.

Time for Diagnosis and Treatment

- Persistent cognitive impairment with marked fluctuations in severity.
- Nocturnal worsening and nightmares.
- More florid delirious episodes with confusion, visual and auditory hallucinations and secondary paranoid delusions.
- Occasional to frequent falls, either due to postural instability or sometimes accompanied by transient disturbances of consciousness.
- Extensive medical screening performed with negative results.

Advancing Disease

- Sudden increases in confusion, psychosis and behavioral disturbance may be precipitated by medication reactions or co-morbid medical conditions.
- Severe neuroleptic sensitivity reactions may provoke the rapid development of rigidity, marked worsening in cognitive functioning, and heavy sedation.
- In cases not receiving neuroleptics or tolerating low dosage of one, the typical natural history is a gradually progressive decline into severe dementia.
- Physical and speech therapy may help maintain functional abilities for some time.
- Increasing behavioral disturbances, including shouting, aggression on approach and evidence of persisting delirium.
- Death is usually secondary to respiratory or cardiac disease, or injuries sustained in falls.

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