

A Comprehensive Approach to Treatment can Significantly Improve the Quality of Life of Patients with the Lewy Body Dementias

by Bradley F. Boeve, M.D.

Lewy body dementia, like Alzheimer's Disease, is not preventable or curable, but by focusing on what we CAN do, rather than what we cannot do, there is much that can be done to allow your patients to enjoy a higher quality of life. In fact, LBD patients tend to have greater cholinergic deficits but less neuronal loss than AD patients, so there is more potential for improvement and/or stabilization using the cholinesterase inhibitors. Additionally, there are good medications for many of the behavioral features of LBD.

In our experience, many LBD patients enjoy significant improvement with a comprehensive approach to therapy addressing cognitive, neuropsychiatric, motor, sleep, autonomic, and other medical issues, and many have remarkably little change from year to year. Clearly, not all patients experience this improvement and slowly progressive course, but for many LBD patients (especially those with little atrophy on MRI), the neurotransmitter deficit appears to drive the illness more than neuronal death. Such patients can improve with therapy, sometimes markedly, and do quite well, all things considered, for many, many years. Perhaps it is the lack of a comprehensive approach that many have not seemed to benefit. Perhaps there are biologic differences between different patient populations that lead to differences in the clinical course, etc. We in the LBDA firmly believe an aggressive and comprehensive approach is necessary with LBD patients, especially early in the illness, and some clinicians may not take that approach.

It pains us greatly to think of the LBD patients who see physicians who have the all-too-frequent view that "this patient has dementia, none of the drugs work so there is little to do, so get your finances in order and plan for a painful next few years when you won't recognize your family, will need to live in a nursing home....." This is the view of so many MDs, including neurologists and psychiatrists, and it is our (LBD specialists) obligation to educate the public and the medical community that LBD is very different than AD, and it is absolutely unacceptable to do nothing or take a nihilistic approach. We must also maintain realistic optimism, since there is almost always

something we MDs can do to affect quality of life - through medications, education, counseling, behavioral modification, etc.

Encourage your patients' caregivers to become good detectives, by carefully studying and identifying medications and other interventions or environmental factors that influence the LBD patient's function/fluctuations.

We are seeking to promote knowledge and understanding that LBD:

- is a relatively common form of dementia;
- is recognizable to the educated eyes;





LBD Requires a Comprehensive Treatment Approach

- can respond to cholinesterase inhibitor +/-psychostimulant therapy, sometimes
- dramatically;
- should not be exposed to conventional neuroleptics;
- quality of life for patients and families can be easonably good for many years.

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A Note from LBDA:

One example of how a comprehensive approach to therapy can yield very positive results can be seen in a recent video clip produced by the Mayo Clinic, featuring Dr. Brad Boeve, one of our Scientific Advisory Council members. Dr. Boeve and his colleagues at Mayo Clinic interviewed a patient and his wife http://www.medicaledge.org/2005march-1.html), who is representative of the sometimes dramatic improvement one can see when a team of clinicians take a comprehensive approach toward therapy, and a patient and caregiver address several important non-medication issues.

Mr. R was confused, paranoid, delusional, hallucinatory, and his wife was very frustrated by the dramatic changes in her previously high-functioning husband. The patient's neurologist, psychiatrist, and internist worked toward establishing the diagnosis, and he improved significantly with Aricept, but his hypersomnolence, sleep attacks, and delusions and hallucinations persisted to some degree. He was then commenced on Provigil, and the next day his hypersomnolence improved and his sleep attacks, delusions and hallucinations stopped, and have been almost nonexistent now for well over a year.

He is also receiving treatment for his parkinsonism (carbidopa/levodopa), a sleep disorder known as REM sleep behavior disorder (clonazepam), and depression (bupropione). His internist is optimizing management of his diabetes, atrial fibrillation, and chronic need for anticoagulation. He and his wife also remain physically and mentally active, do water aerobics, spend quality time with friends and family, and maintain an excellent sense of "realistic optimism." He is not neurologically normal, but he and his wife have an active lifestyle, enjoyed a cruise a few months ago (which would not have been possible prior to these therapies), and this clinical improvement and stabilization and desire to educate the public were their motivations to do this video.

More information on REM sleep behavior disorder can be found at this link (scroll down to video segment B047, and click on video): <u>http://www.medicaledge.org/2001novembervideo.html#3</u>



To learn more about LBD, visit www.lbda.org

LBD Caregiver Link: I-800-LEVVYSOS I-800-539-9767 <u>Ibda@Ibda.org</u>

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