

Living with Lewy Body Dementia

What makes LBD different from other dementias?

Paula Rice Biever - LBD Association Volunteer & Support Group Facilitator

Introduction to Lewy body dementia

Diagnosis: symptoms and treatment

Challenges faced by persons living with LBD and by carepartners

Community and online resources

Leah Forsberg, PhD - LBD Research Center of Excellence - Mayo Clinic

Current medical research and the role of the Mayo clinic as a Research Center of Excellence

Tamara Statz, MA, LMFT - School of Public Health, Center on Aging - University of Minnesota

Current research projects on carepartner and patient support

Angela Lunde - LBD Research Center of Excellence - Mayo Clinic

Finding solutions to the challenges of Lewy body dementia: What I've learned from supporting care partners and persons living with Lewy.

Diagnostic Criteria - Dementia must be present

Essential for a diagnosis of DLB is dementia, defined as a progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational functions, or with usual daily activities.

- Prominent or persistent memory impairment may not necessarily occur in the early stages but is usually evident with progression.
- Deficits on tests of attention, executive function and visuo-perceptual ability may be especially prominent and occur early.

Diagnostic Criteria - Core Clinical Features

- Fluctuating cognition with pronounced variations in attention and alertness
- Recurrent visual hallucinations that are typically well formed and detailed
- REM sleep behavior disorder (RBD) which may precede cognitive decline
- Slowness of movement, rest tremor, or rigidity

Diagnostic Criteria - Indicative Biomarkers

- Reduced dopamine transporter (DaT) uptake in basal ganglia demonstrated by SPECT or PET
- Abnormal (low uptake) ¹²³Iodine MIBG myocardial scintigraphy
- Polysomnographic confirmation of REM sleep without atonia
- Slowness of movement, rest tremor, or rigidity

Diagnostic Criteria - Probable LBD Diagnosis

Probable DLB can be diagnosed if dementia is present along with

a) two or more core clinical features of DLB with or without the presence of indicative biomarkers

**Fluctuating cognition Hallucinations REM sleep behavior disorder
Parkinsonian symptoms: Slowness of movement, rest tremor, and rigidity**

or
b) only one core clinical feature but one or more indicative biomarkers.

**SPECT or PET scan showing decreased dopamine in basal ganglia
Abnormal myocardial scintigraphy
Polysomnographic confirmation of REM sleep without atonia**

Symptoms of Lewy Body Dementia

- REM sleep behavior disorder
- Attention span, visuospatial, executive functioning
- Hallucinations and delusions
- Problems with balance, tremors and rigidity
- Neuropathy
- Sudden drop in blood pressure when standing up
- Difficulties with swallowing and eating
- Incontinence, constipation, diarrhea, digestive issues
- Issues with sleeping and staying alert
- Losing train of thought during conversations
- Short-term memory issues

The overall symptom that affects all of these is fluctuation!

What treatments are available to help?

- Everything that is prescribed is considered off-label.
- There are no drugs that address the cause of Lewy body dementia.
- Drugs are used to help moderate the symptoms people experience.

AVOID HALDOL and other traditional antipsychotics

Refer to the LBDA Medication Glossary for information about various drugs.

Commonly prescribed drugs

- Aricept or Exelon for cognitive issues
- Melatonin and/or a low dose of Klonopin for REM sleep behavior disorder
- Seroquel for agitation and sleep disturbances
- Effexor or Lexapro for depression and anxiety
- Levodopa/Carbidopa (Sinemet) used with caution for Parkinsonian symptoms

Challenges - from persons living with LBD

- Loss of independence - can no longer drive
- Inability to control what they were once in charge of
- Stigma of having hallucinations and delusions
- Difficulty communicating during conversations
- Environmental overstimulation
- Problems sleeping
- Other physical symptoms that limit social activities
- Fear of being a burden
- Medications don't have a predictable effect.
- Apathy and depression

Challenges - from carepartners

- Lack of a road map
- Uncomfortable changes in relationships
- Juggling medications
- Lack of information presented at the time of diagnosis
- Lack of understanding by medical professionals
- Mistreatment in emergency situations, need to advocate
- Better understanding of hallucinations
- Balancing care and work responsibilities
- Lack of sleep and “off-duty” time

The most important challenge . . .

“What would you like to have happen, besides a cure, that would make the biggest difference to you as a carepartner, or as a person living with the diagnosis?”

Persons with LBD and carepartners agreed that better understanding of Lewy body dementia by medical professionals and residential care staff would make the most difference.

Community and Online Resources

LBD Specific Resources

- Support Groups in Minnesota
- LBD Websites
- Facebook pages for LBD Carepartners
- Facebook pages and online resources for Persons with Lewy body dementia
- Videos about Lewy Body Dementia
- Medical Clinics in Minnesota with LBD expertise
- Books

Community and Online Resources

Non-Specific Dementia Resources

- Statewide and County Agencies
- Dementia Care Resources

