


## Young-Onset: Overview of Lewy Body Dementia, the Challenges, the Supports

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## What is Lewy Body Dementia (LBD)?

- **A progressive brain disease**
- Features abnormal protein deposits, called **Lewy bodies**, in the brain
- Named after Dr. Friederich Lewy, a neurologist
- Difference in diagnostic criteria based on timing of symptoms with “One Year Rule”



Lewy body Dementia



Parkinson's disease dementia (PDD)      Dementia with Lewy bodies (DLB)

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## Lewy Body Dementia Statistics


LBD is the **most** misdiagnosed form of dementia

**1.4 Million** Americans affected, mostly adults over age 50

The **second** most common cause of progressive dementia after Alzheimer's disease


Studies indicate that LBD is the **most expensive** form of dementia

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**LBDA**  
LEWY BODY DEMENTIA ASSOCIATION

## Barriers to Diagnosing LBD




**Clinical Picture Can Vary**

- Symptom presentation
- Symptom reporting
- Patient insight



**Clinician-Related Challenges**

- Primary care physicians' familiarity with complex diagnostic criteria
- No referral to specialist
- No referral for neuropsychological testing



**Lack of Widely Available Biological Test**

Diagnosis may be Mixed

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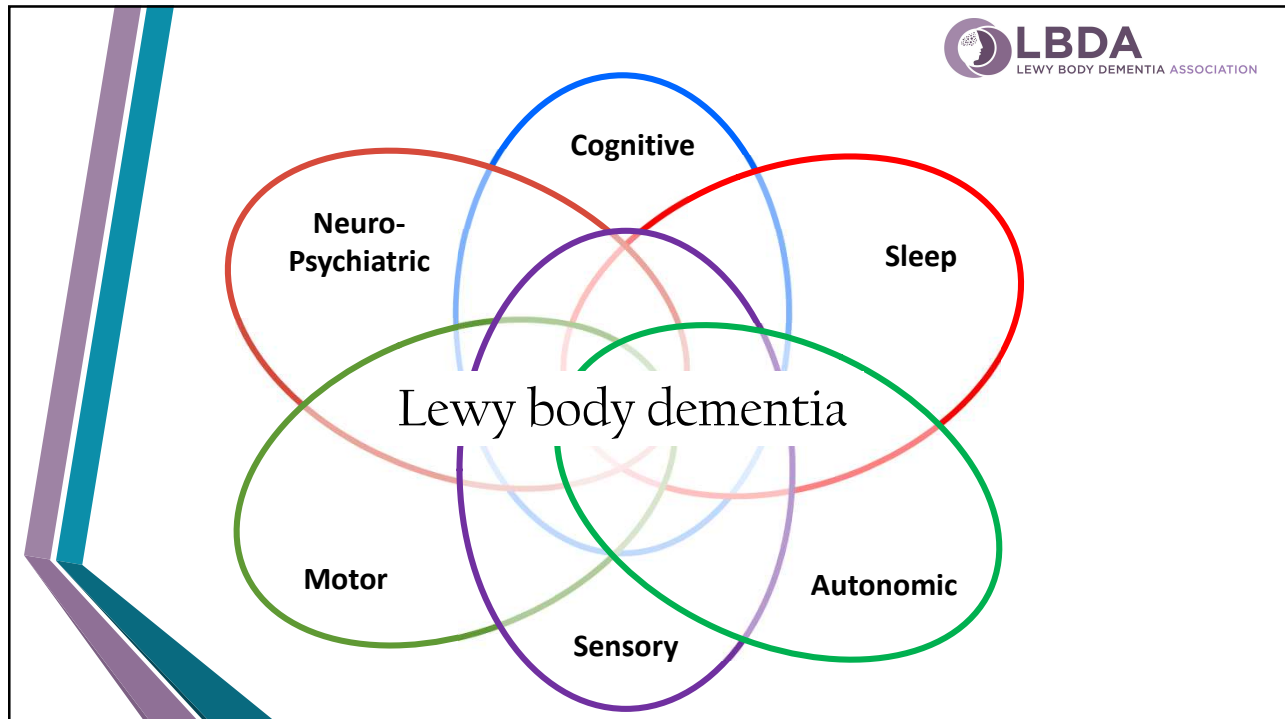
## Dementia with Lewy Bodies

To diagnose someone with DLB, there **must** be enough cognitive decline to impair daily activities, plus **two** of the following features:

Parkinsonism	Visual Hallucinations	REM Behavior Disorder	Cognitive Fluctuations
<ul style="list-style-type: none"> <li>• Slowness</li> <li>• Stiffness</li> <li>• Shakiness</li> </ul>	<ul style="list-style-type: none"> <li>• Well-formed, complex visions</li> <li>• People and/or animals</li> </ul>	<ul style="list-style-type: none"> <li>• Acting out dreams</li> <li>• Can occur decades before other symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Changes in level of alertness or arousal</li> <li>• "Zoning out"</li> </ul>

All of these symptoms can also occur in Parkinson's disease

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## Challenges for those Diagnosed of Young Onset and their Care Partners

### Symptoms affect more than cognitive abilities

- Motor – impaired gait, stiffness, mobility, fall risks (also can be with fluctuations)
- Cognitive – fluctuations may make daily life challenging
- Mood – apathy, depression, anxiety may increase
- Autonomic – blood pressure fluctuations, syncope, incontinence
- Sensory – vision and smell changes
- Sleep -
  - night-time issues such as RBD may also affect sleep for both
  - daytime sleepiness disrupts schedules

### Activities of Daily Living (ADLs) affected sooner in those with LBD

- Due to combinations of symptoms above

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## Challenges for those Diagnosed of Young Onset and their Care Partners

### Altered Perceptions

- Hallucinations, illusions & delusions (can be misdiagnosed as other conditions like schizophrenia)
- Prevalent even in the beginning stages of LBD
- Often first time experiencing and/or supporting someone with these symptoms

### Medication Sensitivity

- Many medications (both Rx and OTC) used in other conditions (and even dementias) can have negative reactions or worsening of symptoms.
- Some medications used to help one set of symptoms may worsen another set of symptoms – and vice versa.

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## Challenges for those Diagnosed of Young Onset and their Care Partners

### Placement difficulties

- Age related restrictions or experience
- Lack of staff-specific training or experience – especially with variety of symptoms, treatments, techniques, and fluctuations
- Providers' resistance to accept with diagnosis and/or with presentation of symptoms

### Changes to Personal and Peer Supports


- Fluctuations difficult for supports to understand
- Professional changes for both person diagnosed and care partners
- Friends may back away with lack of understanding, communication changes, physical needs, etc.
- Faith communities may lack resource or understanding
- Supports specific to LBD understand (lived-experience) limited – but available (such as Lewy Buddies)

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## Why Should Care Providers Know More About Lewy Body Dementia?

- To receive education and be able to provide information – to best provide clarified diagnosis, care, medication management, increased access to research, and supportive techniques with individuals with Lewy body dementia and their care partners from pre-diagnosis through bereavement.
- Connect those served to local resources, appropriate levels of care, financial resources, and advocate within systems as required for what is needed to support their patient and their situation.
- Proactively reduce risks for those served involving fall prevention, emergency planning, crisis intervention, and overall safety
- Improved cost savings, patient outcomes, and risk reduction.

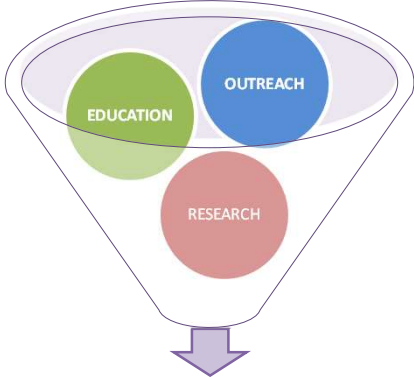
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## LBDA Resources for Individuals, their Personal Supports and Professionals


**National health organization dedicated to:**

- Raising awareness of LBD
- Advancing the diagnosis of LBD
- Promoting scientific advances
- Supporting people with LBD, their families, and caregivers




**Reducing the burden on LBD families**

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## FACING LBD TOGETHER

Increasing Knowledge  
Sharing Experience  
Building Hope



An Introduction to Lewy Body Dementia  
A special publication for people newly diagnosed with Lewy body dementia and those still seeking answers.  
[www.lbda.org](http://www.lbda.org)

## Educational Resources

Visit [lbda.org](http://lbda.org) to request free publications and downloadable resources for the LBD community and professionals.

### Enroll in the Lewy Learning Center

The go-to place for free, on-demand learning for a range of topics on Lewy body dementia.

Visit [lewy-learning-center.thinkific.com](http://lewy-learning-center.thinkific.com)

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## LBDA Volunteer Support

### Support Groups

Important notes regarding LBDA Support Groups during the COVID-19 crisis: Many of our groups meet in senior facilities/healthcare locations and have cancelled their meetings. Most are cancelling in-person meetings and may be meeting via phone/Zoom conferencing. Contact the Support Group Facilitator if you have any questions/concerns about a particular group at this time. In addition, support is just a click away when you connect with others in an online community (Zoom Support Groups link).

Seeking support? Connect with individuals, families and caregivers who are seeking support during this challenging times. With support groups in over 30 states, connecting with other caregivers provides valuable and trusted resources and information for LBDA families. We provide free, confidential support in a group setting to anyone affected by LBDA—whether you are an LBDA caregiver or are a loved one, friend, or professional caregiver of someone diagnosed. To find a support group in your local area, select your state's two letter abbreviation from the drop-down menu and click apply. (If no groups are listed, consider searching one in your community. [Click here](#) to become a volunteer.)


Select the State





Lewy Buddy Program

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## LBDA Lewy Line and Support Email

**LBDA Lewy Line - 800-539-9767**

Those living with symptoms or a diagnosis of Lewy body dementia, care partners, and involved professionals can connect to licensed LBDA Support Services staff through the LBDA Lewy Line or Support email for guidance, information, resources, and connections.

<https://www.lbda.org/lbda-lewy-line/>

**E-mail LBDA Support Services – [support@lbda.org](mailto:support@lbda.org)**

Emails are reviewed and responded to during business hours by LBDA staff.

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