



Knowing Lewy: The First Step to Planning, Advocacy & Community

**Presenter: Rachel Rose, MOT, OTR/L, Education Manager
Lewy Body Dementia Association**

8:15 – 9:00 am

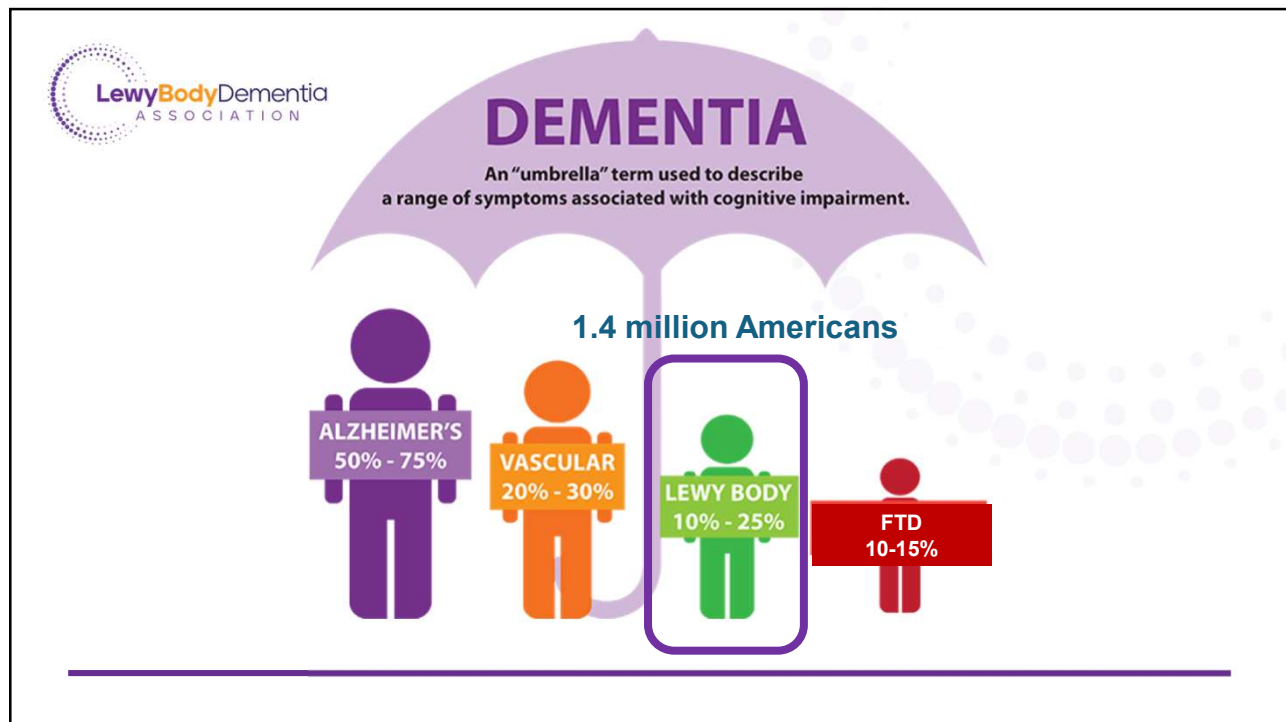
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Goals for this talk...

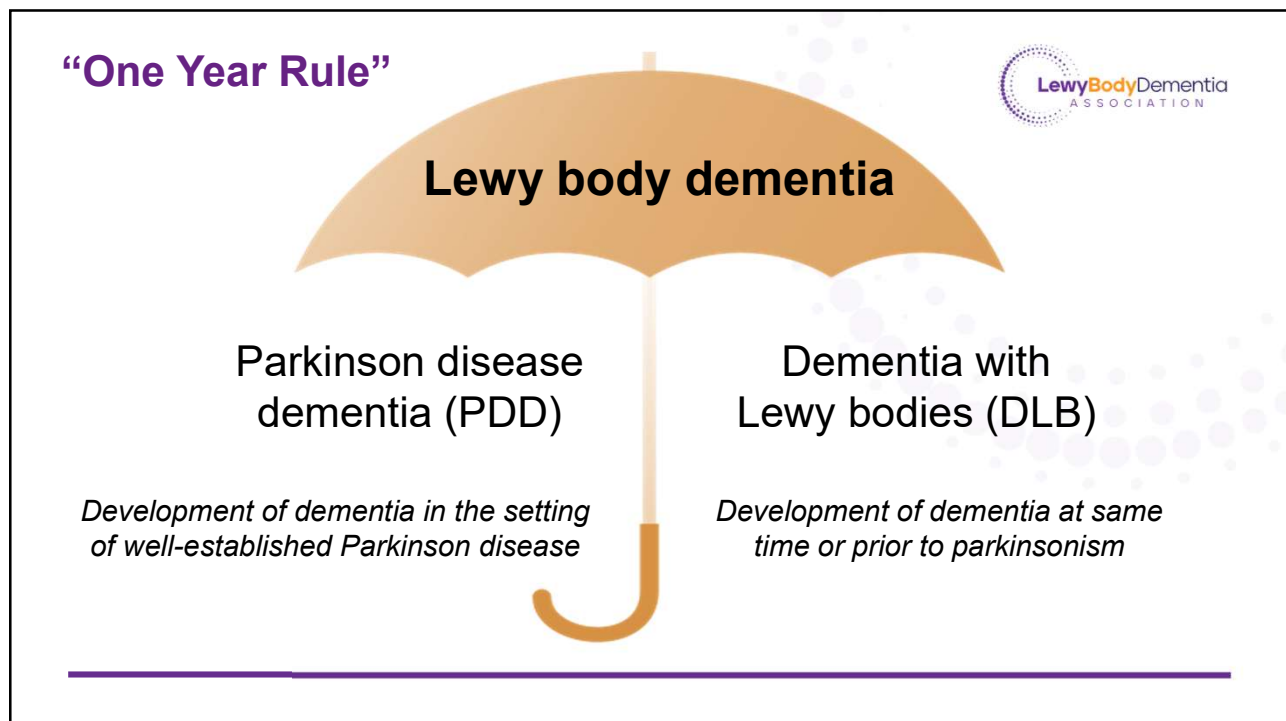


1. Review Lewy body dementia and its unique presentation.
 2. Explain how diagnosis and education can empower individuals and families to make informed decisions and advocate for appropriate care & resources.
 3. Reflect on lessons learned from lived experiences and identify practical sources of support throughout the LBD journey.
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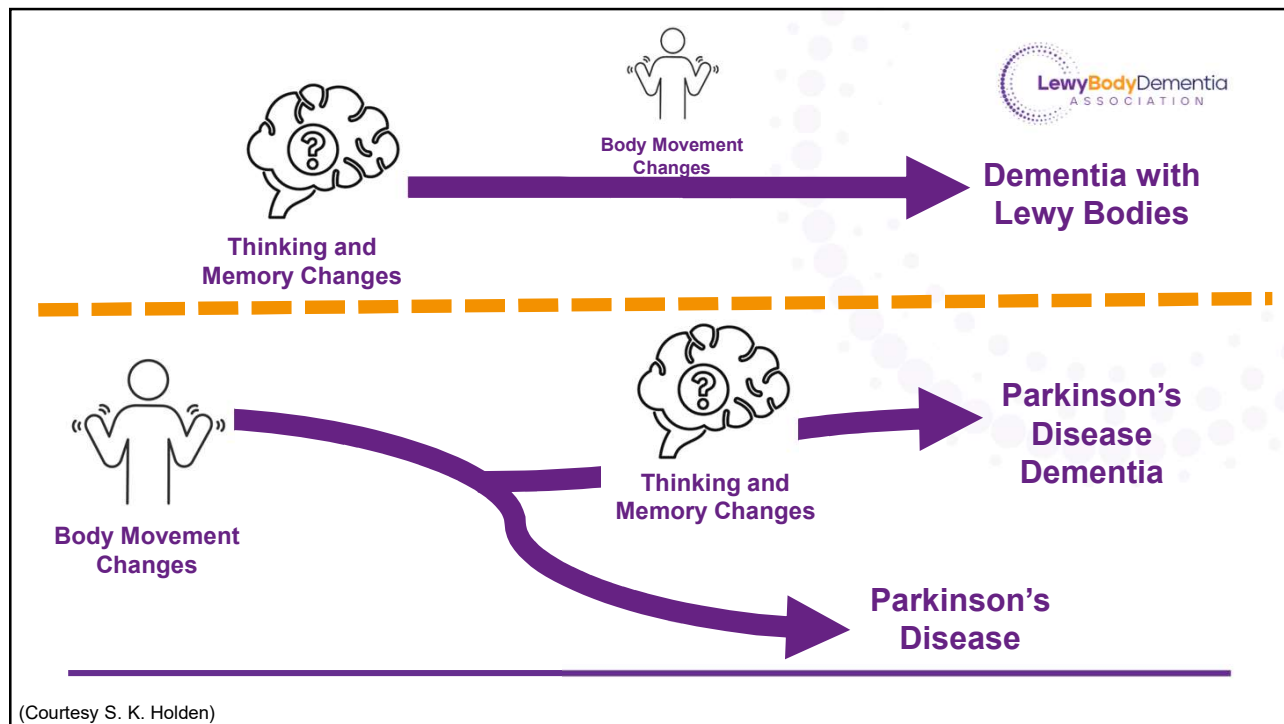
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Barriers to Diagnosing LBD

Clinical picture can vary

- Symptom presentation
- Symptom reporting
- Insight (PLwL or CP)

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

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Receiving a Diagnosis



60%
required at
least 3
physicians

50% of
diagnoses
took 12-18
months

62% of
diagnosing
physicians
were
neurologists

Less than
10 %
diagnosed
by primary
care
providers

78% had
been
diagnosed
with
something
else first

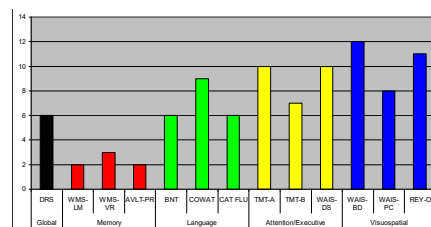
(Galvin et al., 2010)

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Differences in Alzheimer's disease & Dementia with Lewy bodies



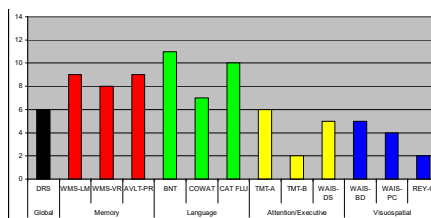
ADem



Impaired on:

- Memory measures
- Language measures

DLB



Impaired on:

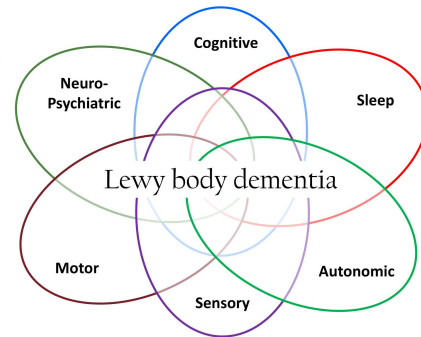
- Attention/Executive measures
- Visuospatial measures

(Ferman et al, Neurology 1999
(Ferman et al, Clin Neuropsych 2006)

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LBD Symptoms

- Progressive loss of cognitive abilities
- Changes in movement
- Behavior and mood changes
- Sleep disorders
- Dysautonomia
- Sensory changes (vision, hearing, etc.)



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It's Not the Same...

- The **loss of independence** appears earlier than what is seen in AD dementia.
- This more rapid decline in functional ability and increasing dependence may **increase the use of resources and the cost of care in LBD** compared with AD.
 - Hospitalizations, falls, urinary symptoms, depression, dehydration, anxiety, psychosis, orthostasis, and sleep disorders.
- **Unique Challenges of LBD:**
 - Misdiagnosed/under-recognized
 - Care partner burden (Difficulty planning, myriad of symptoms, assistance required)
 - Earlier nursing home admissions (~2 years earlier in DLB than AD)
 - Potentially dangerous medication sensitivities



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Current Treatment Strategy:



Goal: Improve quality of life

- Many symptoms can be managed or reduced with medications and therapies.
- Multidisciplinary team care is essential.
- Continued engagement in meaningful activities.



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Why Naming it Matters:



Access to
information to
understand the
changes



Enables
treatment
plans:
medicines,
referrals, etc.



Access to
support
services and
resources



Access to
research or
clinical
trials



Lifestyle
interventions



Future
planning



(Courtesy of Dr. Patel)

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Please welcome today's panel



Michael Laibson
Living with Lewy

Paula Biever
Care Partner



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Resource:



mediflix.com/channels/lewy-body-dementia-association

Mediflix

LewyBodyDementia ASSOCIATION

Understanding Lewy body dementia with Dr. Jori Fleisher explains the complexities of this often-misdiagnosed form of dementia, how it differs from Parkinson's disease, and treatment options available.

Scan QR code to watch videos.

Learn More about the Lewy Body Dementia Association at lbda.org

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