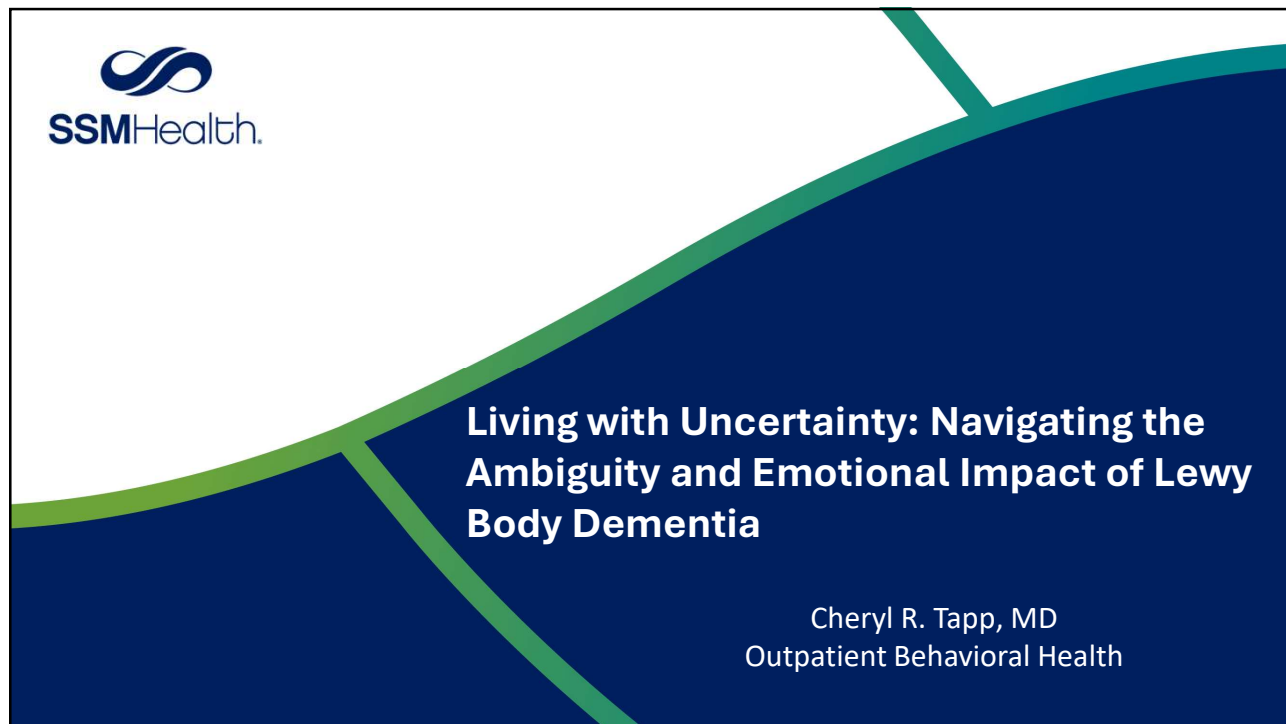




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Objectives

- Outline how symptom variability uniquely impacts individuals and care partners.
- Recognize common emotional responses to ambiguity, including frustration, grief and anxiety.
- Identify logistical strategies and supportive therapies for emotional well-being amid uncertainty.



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**As DLB is a heterogeneous disorder,
healthcare providers have the ability to
diagnose the disease based on the
patient's
individualized clinical presentation and
biomarker profile**

- Fourth consensus report of the DLB Consortium

4

Symptom Variability

- Not everyone has the exact same symptoms
- The list of supporting symptoms from the Fourth consensus report of the DLB Consortium more than 20 symptoms in a wide range of categories
 - 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
 - One or more spontaneous cardinal feature of parkinsonism – these are bradykinesia (defined as slowness of movement and decrement in amplitude or speed), rest tremor, or rigidity
 - Severe sensitivity to antipsychotic agents; postural instability; repeated falls; syncope or other transient episodes of unresponsiveness; severe autonomic dysfunction e.g. constipation, orthostatic hypotension, urinary incontinence; hypersomnia; hyposmia; hallucinations in other modalities; systematized delusions; apathy, anxiety and depression

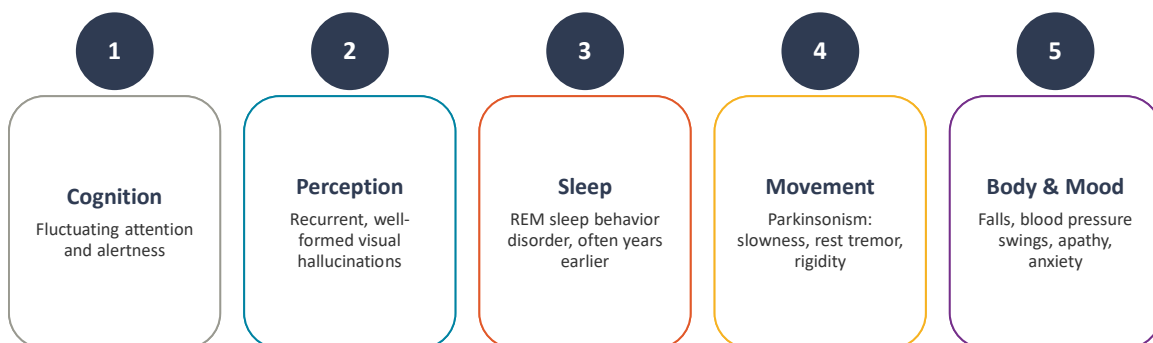


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Symptom Variability

20+ supporting symptoms across many categories — no two people present alike (DLB Consortium, 4th Consensus Report)



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Individual Fluctuations in Symptoms

- Difficulty getting an accurate diagnosis
- No true staging of symptoms can be done
- Requires a lot more adapting and flexibility for caregivers
- Everyday can be an unexpected experience



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Response to Ambiguity

- Emotional and Psychological Reactions
 - **Anxiety and Stress:** The human brain craves certainty, so unclear or unpredictable situations often trigger a threat response in the brain, leading to nervousness, frustration, or fear.
 - **Fight, Flight, or Freeze:** The nervous system treats uncertainty as a potential threat, triggering a survival response.
 - **Ambivalence:** Individuals can experience mixed or conflicting emotions, such as simultaneous frustration and hope
 - **Apathy or Disengagement:** When faced with persistent uncertainty, people may shut down or stop trying to engage.



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Response to Ambiguity

- Emotional and Psychological Reactions
 - Ultimately all of those emotions cumulate in feelings directed inward including
 - Depression
 - Anxiety
 - Guilt
 - Grief

Grief

- Loss of relationship
- Physical changes
- Cognitive changes
- Loss of independence
- Cumulative impact



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Symptoms and Strategies

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Hallucinations

- Visual hallucinations occur in up to 80% of people with DLB and may present early on when the person is experiencing only mild cognitive symptoms. These hallucinations are typically vivid and feature people, children or animals. They can be more real to them than their vision allows.



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Hallucinations

- Don't stress if they are not stressed about it
- Don't tell them they are not there unless they ask
- Assure them that they are safe and move away from the hallucination
- Close the drapes or remove surrounding or distracting items
- Try to find the right amount of stimulation for the moment



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Delusions and Paranoia

- Delusions are fixed, false beliefs that a person holds firmly despite clear and obvious evidence to the contrary
- Paranoia is a state of mind marked by intense, irrational distrust, suspicion, or the belief that others are trying to harm, deceive, or target you

Capgras Syndrome

- Someone firmly believes that a close family member, friend, or pet has been replaced by an identical-looking impostor
- The disconnect is that the person can visually recognize their family member, but they lose the normal emotional feeling of familiarity that should accompany seeing them.

Delusions and Paranoia

- Don't Take it Personally
- Don't argue
- Move to another location
- Make sure your treatment providers know



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Caregiver Emotional Response to Hallucinations, Delusions and Paranoia

- Don't Take it Personally
- This is not something that you can fix, this is a dopamine problem in the brain
- The response can make it harder to dissipate



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Awareness

- Some patients have awareness into their cognitive changes much later in the disease process, especially compared to Alzheimer's patients leading to
 - Self deprecating remarks
 - Anxiety
 - Depression



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Caregivers Emotional Response to Awareness

- Share in their grief and remind them that it is not them but the disease process
- Focus with them on what they can do and what they do remember



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Lack of Smell/Taste

- Can be a safety concern (cannot smell smoke or gas)
- Can lead to loss of appetite
- Can lead to depression (loss of pleasure in eating)
- Talk to doctor about lifting or easing dietary restrictions
- Focus on textures, temperatures or specific flavors
- Concerns over appetite should be focused on weight/muscle mass, not how much is being consumed



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Temperature Regulation

➤ How LBD Affects Temperature Regulation

- **Autonomic Dysfunction:** Abnormal protein deposits damage the nervous system paths that manage automatic body tasks like heart rate and sweating.
- **Extreme Sensitivities:** People with LBD often feel too hot or too cold when the environment changes only a little bit.
- **Communication Loss:** The brain may not realize the body is overheating or freezing, so the person will not adjust their clothes or drink water.
- Health Risks to Watch For
 - **Hyperthermia:** High body heat can lead to heat exhaustion or heat stroke during warm summer days.
 - **Hypothermia:** Trouble sensing cold can cause dangerously low body temperatures in chilly weather.
 - **Medication Side Effects:** Heat can change how the body processes drugs, making LBD symptoms worse.
- Check the room temperature often instead of relying on the person to say they are uncomfortable.
- Offer water frequently to prevent dehydration.
- Help them add or remove layers of clothing as the weather changes.



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Parkinsonian Symptoms

➤ Tremor – Always variable

- ~~Consider weighted utensils~~ JW1 place with next bullet
- Consider adaptive utensils and seek guidance from an occupational therapist for individualized recommendations.
- Finger foods
- Cups with lids
- Dignity issues with being fed, pureed food, clothing protectors, “sippy cups”

Parkinsonian Symptoms

➤ Freezing - temporary, involuntary inability to move

- Puts at risk for falls
- Happens when transitioning from standing to walking, walking through doorways, turning a corner, turning around or stepping from one type of surface to another JW1 add below
- May impact use of hand when writing, eating, etc.
- Can be related to lower levels of Parkinson’s medication

Slide 23

JW1 There is no evidence for weighted utensils and in my practice I never found them helpful for any patients. Please replace with "Consider adaptive utensils; consult with OT for specific recommendations for you"

Julia Wood, 2026-09-08T20:43:55.412

Slide 24

JW1 Can also include freezing of the upper limb, impacting bringing utensil to mouth. See this article per FOUL in PD

Heremans, E., Nackaerts, E., Vervoort, G., Vercruysse, S., Broeder, S., Strouwen, C., Swinnen, S. P., & Nieuwboer, A. (2015). Amplitude Manipulation Evokes Upper Limb Freezing during Handwriting in Patients with Parkinson's Disease with Freezing of Gait. PloS one, 10(11), e0142874. <https://doi.org/10.1371/journal.pone.0142874>

Julia Wood, 2026-09-09T17:35:15.812

Parkinsonian Symptoms

➤ Freezing –

- Don't try to assist, be patient, say "we aren't in a hurry"
- March or goose step
- Shift the weight of your body from one leg to another.
- Use music and step in time with the rhythm or try humming, singing or counting.
- Imagine a line to step over or focus on a target on the floor to step on
- Turn by walking half a circle or square instead of by a pivot turn.



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Cognitive Symptoms

- **Shifting Awareness:** A person may stare into space, seem extremely drowsy, or struggle with speech one moment, then appear entirely clear
- **Timeframe:** These episodes vary wildly, lasting from a few seconds to hours, days, weeks with no fixed pattern.
- **Delirium-Like State:** Changes often mimic sudden delirium, making the person seem completely unengaged or confused before returning to baseline.
- **Concentration:** Noticeable trouble with focus, multitasking, and problem-solving rather than just primary memory loss
- **Contrast with Alzheimer's:** Unlike Alzheimer's disease, where daily cognitive function remains relatively stable, LBD features drastic "good days and bad days" or even "good and bad moments".



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Caregivers Emotional Response to Cognitive Symptoms

- Don't try to figure it out, you can spend a lot of time and energy looking for patterns that don't exist
- Don't take it personally
- Have a plan if an "episode" does happen



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Flexibility is the Key

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Individualized Treatment Plans

- Must address the unique symptoms of patients with Lewy body dementia
- Must be adapted as patient's needs change
- Always start with ruling out medical issues like infections, constipation, injuries and pain
- Avoid overstimulation or under stimulation
- Always have a Plan B, C and D



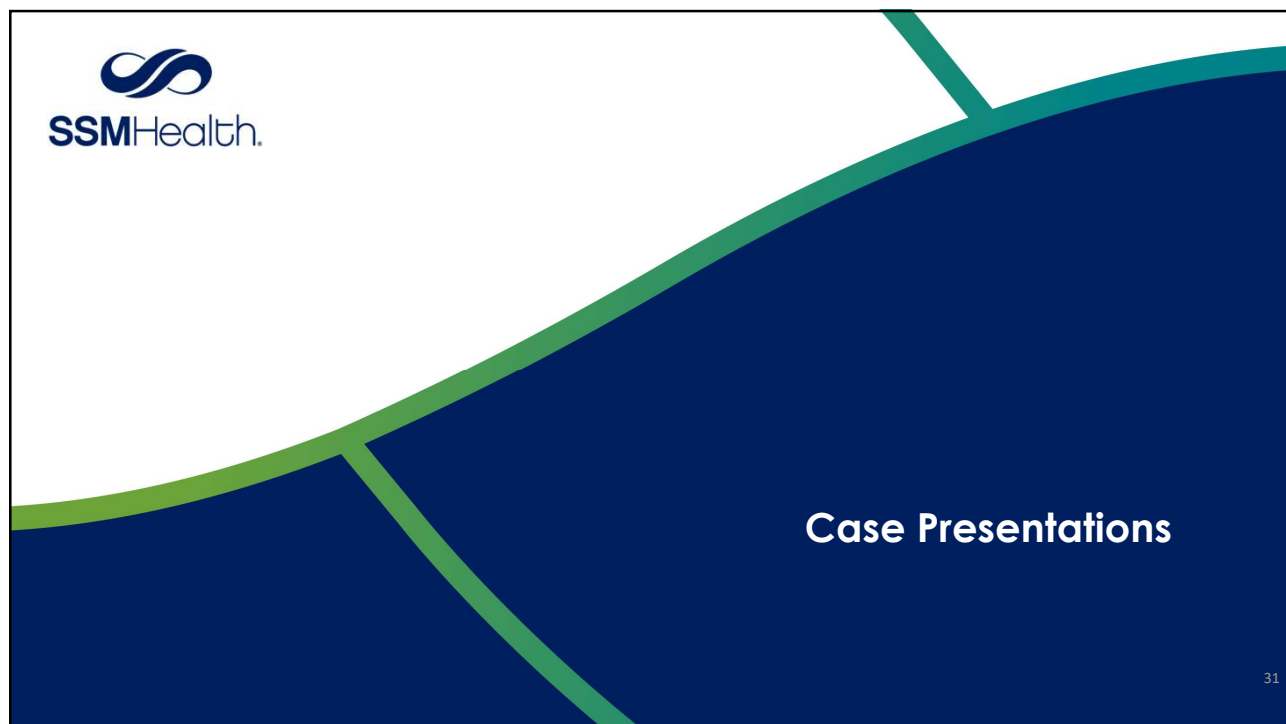
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Individualized Treatment Plans

- Fluctuations in confusion, sleepiness and attention
- Parkinson's symptoms
- Hallucinations
- Paranoia or delusions
- Impulsiveness
- Acting out dreams



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Case Presentations

➤ John

- Came with a diagnosis of Lewy body but looked too good and did so well on my cognitive testing that I dismissed the diagnosis
- On the 4th visit a reinstated the diagnosis of DLB after presenting differently at each appointment
- Needed Flexible Scheduling for appointments, activities and cares

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Case Presentations

➤ Charles

- Visual Hallucinations in the yard
- Needed Flexible Schedule for activities and cares



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Case Presentations

➤ Suzanne

- Was initially diagnosed with Parkinson's disease until had some neuropsychological testing done
- Dopaminergic agents were not helpful and made her hallucinations and delusions worse
- REM Sleep Disorder, falls (some due to freezing) and worsening paranoia over husband caused her to be placed in a facility



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Case Presentations

➤ Larry

- Presented with powerful hallucinations and weight loss due to anosmia
- Changing him to all finger foods and using sweeteners was most helpful to helping him maintain his weight



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Contact SSMhrandsupport@ssmhealth.com with any questions about this template.



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