Lewy Body Dementia

The Importance of Comprehensive Care and Support

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
Learning Objectives

- Participants in this webinar will be able to:
  - List three symptoms of LBD
  - Identify two ways LBD is different from Alzheimer’s disease
  - Identify one class of drugs to be avoided in LBD
Dementia: The Basics

- **A general term, not a disease**
  - Cognitive decline severe enough to interfere with daily life

- **Affects**
  - Memory, language, executive function, judgment, attention, visuospatial skills
  - May include behavioral symptoms

- **Common assumption:**
  - Dementia = Alzheimer’s disease

- **Reversible and treatable causes**
  - Medical conditions like thyroid disease
  - Drug reactions
  - Brain tumor
  - Subdural hematoma
  - Hydrocephalus

- **Progressive and irreversible causes**
  - Alzheimer’s disease
  - *Lewy body dementia*
  - Vascular dementia
  - Frontotemporal dementia
Lewy Body Dementia Is…

- A common progressive brain disorder
- **The most misdiagnosed form of dementia**
  - Often diagnosed first as
    - Alzheimer’s disease
    - Parkinson’s disease
    - A psychiatric disorder
- Associated with abnormal protein deposits in the brain
  - These deposits are now called **Lewy bodies**, named after Dr. Friedrich Lewy, a neurologist
Lewy Body Dementia is NOT a Rare Disease

- **2nd most common form of dementia** after Alzheimer’s disease
  - The **most frequently misdiagnosed** form of dementia
  - Affects approximately 1.4 million in U.S.
  - Affects men more frequently than women
  - Age of onset has a wide range, 50-85 years old
LBD is an Umbrella Term

Lewy body dementia

Parkinson’s disease dementia (PDD)  dementia with Lewy bodies (DLB)
LBD at a Glance

- Dementia
- Parkinsonism
- Psychosis and mood disorders
- Sleep disorders
- Autonomic dysfunction
The Importance of Early Diagnosis

- Comprehensive clinical care improves quality of life
  - More responsive to cholinesterase inhibitors
- Minimize risks for medication side effects
  - Antipsychotics
  - Benzodiazepines
  - Sedatives
  - Narcotics
  - Medications for parkinsonism
  - Anesthesia
  - Certain over-the-counter medications
- Proactive caregiver education, support and referral to resources
Today’s Difficult Reality

- **Complex to diagnose** –
  - Presenting symptoms vary
  - Typically requires a specialist

- **Challenging to treat**
  - Severe medication sensitivities
  - Treatments are prescribed off-label

- **Not on the public’s radar**
  - Most people first hear of LBD at the time of diagnosis
  - Caregivers must become educators and strong advocates

- **LBD and its medication sensitivities are unfamiliar to many healthcare providers**
  - Especially emergency room physicians, hospitalists
    - **Request neurology consult** if going to the ER for behavioral concerns
YOU Can Be the Messenger of Hope

- For the person with LBD – “ASAP”
  - Accept your diagnosis
  - Socialize!
  - Have a positive Attitude
  - Find a new Purpose in life
  - As Soon As Possible

- For the person with LBD and their caregiver
  - The importance of self-education and access to resources
  - Prioritize the wellbeing of the caregiver
  - Connect with the LBD community
  - Recognize and reduce stress
  - Comprehensive clinical care improves quality of life
Strategies for Daily Life
Strategies for Daily Life

- **Cognitive Symptoms**
  - Forgetfulness
  - Trouble with problem solving or analytical thinking
  - Difficulty planning or keeping track of sequences
  - Reduced attention
  - Disorganized speech and conversation
  - Difficulty with sense of direction or spatial relationships between objects

- **Robert’s Example**

- **Strategies**
  - Medications developed for Alzheimer’s disease
  - Counseling may help adjust to the diagnosis
  - Slow down
  - Rest when mentally tired
  - Adjust expectations
  - Learn to accept help
Strategies for Daily Life

- **Fluctuations**
  - Concentration, alertness
  - Episodes of confusion
  - Excessive daytime sleepiness

- **Robert’s Example**

- **Strategies**
  - Psychostimulants may help
  - Be flexible and patient
  - Schedule in a nap
Strategies for Daily Life

- **Parkinsonism**
  - Rigidity or stiffness
  - Shuffling walk
  - Balance problems or falls
  - Tremor
  - Slowness of movement
  - Decreased facial expression
  - Change in posture
  - Reduced voice volume and eventually problems swallowing

- **Robert’s Example**

- **Strategies**
  - Slow down to give your brain time to sync up with your movements
  - Carbidopa-levodopa may help
    - NOTE: May worsen hallucinations
  - Physical therapy
  - Occupational therapy
  - Speech therapy
  - Assess the environment for safety
Strategies for Daily Life

- **Autonomic Dysfunction**
  - Dizziness or fainting
  - Temperature regulation
  - Urinary incontinence
  - Constipation
  - Unexplained blackouts or transient loss of consciousness

- **Robert’s Example**

- **Strategies**
  - Compression stockings, add salt to the diet, adequate hydration
  - Dress in layers
  - Toileting schedule, explore alternates to medications
  - Stool softeners, added fiber
  - Monitor and call the doctor with concerns.
Strategies for Daily Life

• **Sleep Disorders**
  - Acting out dreams, sometimes resulting in injury
    • called REM sleep behavior disorder, or RBD
  - Insomnia
  - Restless leg syndrome

• **Robert’s Example**

• **Strategies**
  - Clonazepam or melatonin for RBD
  - Assess injury risks
  - Find a balance with naps in the daytime
  - Eliminate caffeine after dinner
Strategies for Daily Life

- **Behavior and Mood**
  - Hallucinations
  - Delusions
  - Depression
  - Apathy
  - Anxiety

- **Robert’s Example**

- **Strategies**
  - Cholinesterase inhibitors are part of the long term treatment strategy
  - Accept their reality
  - Respond to their emotions
  - Redirect their attention
  - Consult the physician if behavior suddenly worsens
Assessing and Treating Acute Psychosis

1. Assess for pain, infection, other medical causes
2. Use cholinesterase inhibitors as part of the long term treatment strategy
3. Review, reduce, eliminate select medications (i.e. carbidopa-levodopa, benzodiazepines)
4. Assess the environment – interpersonal dynamics and physical triggers like television, mirrors
5. Use non-pharmacological methods – communication strategies, redirection
6. Consider use of an antidepressant
7. *Use atypical antipsychotic medications cautiously and monitor for side effects*

**DO NOT USE TRADITIONAL ANTIPSYCHOTIC MEDICATIONS**
## How is LBD different from Alzheimer’s

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<thead>
<tr>
<th></th>
<th>Alzheimer’s disease</th>
<th>Lewy body dementia</th>
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</thead>
<tbody>
<tr>
<td><strong>Proteins:</strong></td>
<td>Amyloid and tau</td>
<td>Alpha-synuclein</td>
</tr>
<tr>
<td><strong>Symptoms:</strong></td>
<td>Prominent memory problems</td>
<td>Memory may be relatively spared in early stage</td>
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<td>Different changes in thinking</td>
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<td></td>
<td></td>
<td>Many other symptoms not common in Alzheimer’s</td>
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<tr>
<td><strong>Early differentiating signs:</strong></td>
<td></td>
<td>REM sleep behavior disorder</td>
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<td>Visual hallucinations in early stage</td>
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### How does LBD differ from Parkinson’s?

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<td><strong>Protein:</strong></td>
<td>Alpha-synuclein</td>
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<tr>
<td><strong>Brain areas affected:</strong></td>
<td>Substantia nigra</td>
<td>Cortex and other areas of the brain, including substantia nigra</td>
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<td><strong>Functional ability always affected:</strong></td>
<td>Movement</td>
<td>Cognition</td>
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<td></td>
<td></td>
<td>Must have other LBD symptoms for diagnosis</td>
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<tr>
<td><strong>May also affect:</strong></td>
<td>Cognition - may have mild changes in thinking at diagnosis</td>
<td>Movement - but may not show obvious parkinsonism in early stage</td>
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<td>May later develop dementia</td>
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**Summary:**
- **Protein:** Both Parkinson’s disease and Lewy body dementia involve Alpha-synuclein.
- **Brain areas affected:** Parkinson’s disease affects the Substantia nigra, whereas Lewy body dementia affects the Cortex and other areas of the brain.
- **Functional ability always affected:** Movement in Parkinson’s disease corresponds to Cognition in Lewy body dementia.
- **May also affect:** Parkinson’s disease may lead to mild changes in thinking at diagnosis and later develop dementia. Lewy body dementia may not show obvious parkinsonism in the early stage but will eventually develop dementia.
Important Practical Matters
Preparing for the Office Visit

**Advice for the Family**
- Be a good detective
- Use LBDA’s Comprehensive Symptom Checklist*
- Be a strong advocate for yourself or the person with LBD

**Suggestions for the Provider**
- Speak to the patient directly
- Ask what the most bothersome symptoms are
  - Prioritize treating those first
- Listen to the caregiver for signs of depression and burnout
- Refer to PT, OT, speech early
- Be proactive with a referral to hospice
  - Average life expectancy is 5-7 years from time of diagnosis

* https://www.lbda.org/content/comprehensive-lbd-symptoms-checklist
Driving and LBD

- **Risk**
  - Reduced attention
  - Slowed thinking
  - Visuospatial skills reduced
  - Visual hallucinations
  - Motor changes
    - Rigidity, slowed movements
    - Myoclonic jerks

- **Strategies**
  - Caregivers should trust their own judgment
  - Contact the provider in advance if there are safety concerns
  - Let the provider serve as ‘the bad guy’
  - Use friends, family and senior transportation services
Caring for the Caregiver

- **Risks**
  - Depression
  - Anxiety
  - Isolation
  - Self-doubt
  - Burnout

- **Causes**
  - LBD: disrupted sleep, behavioral changes, fluctuations, safety risks
  - Delayed diagnosis, healthcare providers unfamiliarity with LBD
  - Low public awareness
  - Reluctance to ask for and accept help
  - No familiarity with community resources like respite care

- **Robert’s Example**

- **Strategies**
  - Emotional support network
    - Friends and family
    - LBD support groups and online communities
    - Counselors
    - Religious organizations
  - Early referral to community resources
  - Self-education on LBD
  - Embrace their role of patient advocate
Refer Families to Community Resources

- Educate families early about:
  - The availability of home health services
  - The importance of respite care
- Long term care
  - Admission is generally earlier in LBD than Alzheimer’s
  - Commonly driven by:
    - Parkinsonism
    - Behavioral changes
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