Appreciating the Common Changes, Symptoms and Challenges of Lewy Body Diseases:
Diffuse Lewy Body Dementia or Dementia with Lewy Bodies
And
Parkinsonian-Related Dementia

What Do We Know about Lewy Body Disease Conditions in 2020?
- It was not until 2000 that there was much chatter in the scientific research world about Lewy body disease, although it was first identified by Dr Lewy in 1910.
- Historically, LBD was considered to be very rare, only about 2% of people with dementia would have Lewy Body dementia, others had Parkinsons with Alzheimers or something else.
- Just a few years ago, the major category switched from Parkinsons-related dementias to Lewy body diseases and there was a causal link noted.
- In the first 15 years of the 21st century, alpha-synuclein malformed proteins and microglial cell malformations have been more carefully explored and determined to be causative in both Parkinsons disease and Lewy Body dementia, as well as implicated in Multi-System Atrophy.

What has changed in the research and care side of the street in the past five years?
- The NIA and the LBDA have been instrumental in gathering researchers and governmental agencies together to fund and support Centers of Excellence to study conditions related to diagnosis and management of the medical aspects of Lewy body related conditions; there are now 25 centers.
- There is an estimation that between 15-30% of all dementias have some LBD or significant microglia cell degeneration or alpha-synuclein malformations.
- There has been increased public awareness of LBD since the self-inflicted death of Robin Williams. Although he was being treated for Parkinsons and mental health challenges, was actually struggling desperately with LBD, without any knowledgeable support or provider recognition of the condition.
LBD is probably the second or third most common dementia category

- With newer examination techniques and assessment protocols, early identification and discrimination from other conditions is both possible and reasonable
- Presence of some key functional symptoms is indicative of probable LBD; however, definitive LBD can only be verified at autopsy, although accurate symptom identification ends up being about 90-95% accurate
- In 2006, the diagnostic criteria for Parkinson Disease Dementia (PDD) was established
- In 2017, the diagnostic criteria for Dementia with Lewy Bodies (DLB) was revised and published.
- DLB is the most missed, misdiagnosed, and mismanaged of all dementias.

Diagnosis of LBD:

LBD is currently given as a probable diagnosis by presence of patterns of clinical symptoms, but according to research:
- It can be detected with LP in spinal fluid
- It can be detected with PET scans
- It can’t be seen as well with CT scans or MRI
- It does not yet have a ‘genetic test’

LBD Can Be Missed If:

- The health care provider is not looking for it
- The health care provider is mostly familiar with Parkinsons and Alzheimers
- The symptoms are not ‘on’ when the MD sees the person
- The person is on certain meds or is on heavy doses of meds for behaviors already
Who Gets LBD?

- Genetic component, but not consistently, however
- Slightly more males than females right now
- Possibly slightly more African-American risk than Caucasian risk
- Younger onset than Alzheimers: 50-85+
- Duration from first symptoms: 7-9 years or 7-12 yrs

More About Symptoms of LBD:

Visual Disturbances:
- Hallucinations that involve animals, insects, adults, or children
- Looking at the edges or things and trying to touch or trace along imaginary lines
- Seeing images that are distorted in position and depth perception
- Seeing a faint image over the real world
- Worse in the afternoon and evening
- Difficulty figuring out how to use objects and tools

Why?

Anti-psychotic medications are used to try to manage symptoms:

- 50% of people living with LBD have drug hypersensitivity:
  - Irreversible changes are common
  - Changes can and do affect the extrapyramidal nervous system (loss of ability to move against gravity, stay upright, react to the world around, and coordinate actions or reactions)
  - Changes can and do affect the sympathetic and parasympathetic nervous systems (systems that support life – BP, HR, BS, peristalsis, and B&B function)
Changes of Note for DLB:
- Changes fluctuate – symptoms present ↔ symptoms absent!
- Executive Control Center changes = episodes of pre-frontal changes
- Speech, comprehension, and facial recognition changes = episodes of temporal lobe changes
- Coordination, balance, and tactile sensitivity changes = episodes of frontal-parietal lobe and cerebellar changes
- Olfactory, gustatory, auditory, tactile, and vestibular sensory processing changes = episodes of changes in the uncus, frontal, temporal, parietal lobes and cranial nerves
- Visual processing, perception, and foreground-background changes = episodes of occipital lobe changes
- Homeostasis changes = episodes of changes in the primitive system and wiring that supports basic functions such as BP, HR, BS, respiration, pain reactions, and emergency reactions to threat

Comments and Thoughts from PLwD
Barney and Lauren

Mis-diagnosed or Missed DLB Is Dangerous and Can Be Deadly
More About Symptoms of DLB:

Delusional Thinking:
- Fixed beliefs that are false
- Frequently involve sexual or abusive beliefs about family or caregivers
- Telling ‘confabulated’ stories about themselves or others
- Other thought processes can seem reasonable and accurate

Problems with Sleep:
- 50% will have long-term insomnia issues
- Many will not be able to sleep for 4-5 days in a row, then will oversleep
- Many will ‘cat nap’ only, mostly in daytime hours
- The lack of sleep can worsen mood, behavior, skill
- May become motorically agitated when up for long hours: pacing, lapping, or seeking exits

Thinking Problems:
- Think dreams really happened
- Can’t get into REM sleep: walking dreams
- May be more paranoid: thinking others are out to hurt or ‘get them’
- Easily angered or upset
- Intolerant of others
More About Symptoms of DLB:

Sensory Changes:
- Hypersensitive to touch
- Hypersensitive to movement
- Hypersensitive to textures, temperatures, tastes
- Hypersensitive to sound/noise
- Easily overwhelmed by what is going on around them: may seek more private and quiet spaces

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Most Concerning DLB Symptom:
- 50% of people with LBD are hypersensitive to anti-psychotic medications
- Haldol, risperidone, quetiapine can be dangerous and/or deadly: damage extrapyramidal system
- Movement ability can be damaged and not recovered
Parkinson's Disease Dementia:
- Typically begins 5-8 years after motor symptoms start
- About 1 out of 100 people develop Parkinson's Disease after age 60,
- By 8 yrs into the disease 80% of people will have some form of beginning brain change — later onset of change is more consistent with PDD
- Early movement problems — alpha-synuclein abnormalities are active in the substanta nigra versus in the core of the brain and throughout the cortex.
- Problems with attention, logical thinking, and visual-perceptual skills

Symptoms Consistent with PDD:
- Episodes of rigidity—difficulty getting moving
- Bradykinesia — slowed movement with cogwheeling
- Resting tremor — resolves with action
- Reduced ability to attend and stay alert
- Trouble with sleep, less or loss of REM sleep
- Postural instability, shuffling steps with falls, and episodes of syncope
- Recurrent visual disturbances — seeing detailed images not present
- Problems with blood pressure, urinary incontinence, and constipation
- Biomarkers — reduced dopamine transporters, PET scan with a tracer can help sort between PD and AD, sleep eval for reduced REM sleep

More Present in PDD:
- Apathy — decreased spontaneity, motivation, purposeful activity
- Personality shifts — more depressed or anxious
- Delusions — paranoid — infidelity, theft, or people in the home
- Excessive daytime sleepiness
- Not able to process visuospatial material or information
- Difficulty recalling info and learning new info
- Trouble finding words and following complex sentences
Common Changes:

**Diffuse LBD or Dementia with Lewy Bodies**
- Fluctuations in attention and ability to focus
- Fluctuations in speed and clarity of thinking and reasoning
- Episodes of insomnia or restless sleep – pattern changes
- Episodic falls or balance challenges

**Parkinsons Disease Dementia**
- Movement disturbances
  - Resting tremor
  - Cogwheeling rigidity
  - Bradykinesia
- Slowed movement
- Slowed thinking
- Slowed speech
- Soft speech with limited deep breathing
- Difficulty retrieving memories

Early Common Challenges:

**Diffuse LBD or DLB:**
- Sustaining previous work life relationships
- Driving and community mobility
- Managing all the details of life
- Sleep
- Following regular schedules when episodes happen
- Episodic symptoms that make life hard
- Hard to tolerate busy environments and high sensory experiences

**Parkinsons Disease Dementia:**
- Mobility – restlessness, slowed movement, loss of stride and full steps, stumbles and falls
- Slowing of function
- Difficulty expressing emotion with emphasis due to changes in motor responsiveness
- Difficulty speaking up and out
- More trouble staying involved in conversations and activities
- Activities that require coordinated, detailed, sequenced actions

Mid-Dementia Challenges:

**Diffuse LBD or DLB:**
- Difficulty sustaining relationships
- Reduced mobility – falls
- Not eating and lack of appetite – weight loss – nourishment issues
- Sleeplessness - dreams
- Not following regular schedules when episodes happen
- Syncopal episodes
- Avoiding busy environments and high sensory experiences
- Not doing self-care regularly or tolerating self-care routines
- Capgras episodes

**Parkinsons Disease Dementia:**
- Mobility – restlessness, slowed movement, loss of stride and full steps, stumbles and falls
- Getting stuck during functional tasks
- Difficulty expressing emotion with emphasis due to changes in motor responsiveness
- Difficulty speaking up and out
- More trouble staying involved in conversations and activities
- Reduced engagement in many activities that require hand skills, rotational actions, or reciprocal actions
- Trouble chewing and swallowing a variety of food items
- Anxiety, apathy, or depressive symptoms make life problematic
Late Dementia Challenges

**Diffuse LBD or DLB:**
- Losing many relationships
- Not able to engage in many activities
- Immobility – head injuries, fractures – falls
- Limited eating and lack of appetite – weight loss - nourishment issues
- Sleeplessness - frightening dreams
- More awake at night than during the day
- More and longer syncopal episodes
- Not able to tolerate busy environments and high sensory experiences
- Not doing self-care not tolerating self-care routines
- Contractures and difficulty using hands or moving

**Parkinsons Disease Dementia:**
- Loss of mobility – restlessness, slowed movement, loss of walking ability, falls
- Inability to actively do many tasks
- Difficulty speaking and expressing emotion with emphasis
- Difficulty speaking and comprehending
- Disconnecting during conversations and activities
- Very little engagement in activities that require hand skills, rotational actions, or reciprocal actions
- Trouble chewing and swallowing a variety of food items, extreme weight loss and dehydration
- Anxiety, apathy, or depressive symptoms make life hard

**Hands-On Skills for LBD:**
- Slow down!!!
- Simplify requests: single steps
- Start over fresh if ‘stuck’
- Try using rhythm and music to help to encourage movement
- Make sure the person has clear visual cues and simple verbal info before you touch them
- Use firm pressure, not lots of light touch or moving touch

**More Hands-On Skills for LBD:**
- Use Hand-under-Hand® if hands on assist is needed
- In later stages, be aware of visual limitations
- Do one thing at a time
- Allow more time for transitions
- Consider modified diets sooner
- Identify fluid preferences and monitor adequacy even early in the condition
- Consider guided ambulation rather than a walker during episodes of falls
Environmental Supports:
- Moderate stimulation
- Not too loud or too quiet
- Not too crowded or too empty
- Not too hot or too cold
- Not too busy or too still
- Not too boring to too stimulating
- Eliminate sharp edges and tight spaces

Work to figure out what is just right for that person!

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Overall with Lewy Body Dementia:
- Movement problems, falls, and falls with injury
- Visual Disturbances – shapes and movement
  - Hallucinations: animals, children, people, insects
- Fine motor problems: hands, swallowing
- Episodes of rigidity or syncopal episodes
- Waking nightmares or insomnia with following day sleeping
- Thinking that is illogical or inaccurate: delusional thinking
- Confabulation related memory changes
- Fluctuations in abilities
- Drug responses can be extreme and strange
  - Can become toxic, can die, can become unable to move
  - Can have an opposite reaction