

## Dementia with Lewy Bodies (DLB) *aka Lewy Body Dementia (LBD)*

### **What Do You Need to Know?**

- It is not the same as Alzheimer's disease -*some similar symptoms, others are very different*
- Early symptoms are frequently be missed or misunderstood, *even by medical professionals.*
- The use of certain medications (anti-psychotics, anti-anxiolytics, sleep aids, Parkinsonian meds) needs to be more carefully considered, due to possible very serious side-effects for people with DLB
- Progression of DLB may look very different than other forms of dementia.
- It is possible to have a combination of DLB and other dementias, especially common is DLB plus Alzheimer's Disease.
- It can begin at much younger ages than typical Alzheimer's (50-55 versus over 70)
- It may look more like Parkinson's Disease than a traditional dementia
- It will seem to 'come and go' in early stages, you may wonder if you are imagining things.
- Unexplained rigidity, falls, loss of consciousness, or problems with hand use, or difficulty swallowing are often the first symptoms noticed, combined with episodes of visual hallucinations or delusions. New learning and memory problems are generally **not** the first problems noted.

### **What Is It???**

- It is a neurological condition that progressively damages then destroys brain tissue.
- It mimics a combination of Parkinson's and Alzheimer's diseases. It is unique, but suspected of being related to both.
- There are growths of lumpy protein bodies mostly in nerve cells in the cortex of the brain (the gray matter) that makes up the outer layer of the brain and deep in the mid brain or brain stem.
- This damage typically results in problems with movement (both fine and gross motor abilities), sensation, hallucinations & delusions, reasoning and judgment, REM sleep, sudden autonomic changes (loss of consciousness, drops in blood pressure, respiratory and heart rate, and temperature), and acute confusion and attention changes.
- The severity and presence of symptoms will fluctuate and is inconsistent because it affects the chemistry of the brain before it alters the structure of the brain permanently.
- There is not a specific test that can distinguish LBD from other conditions with shared symptoms.
- Early detection and diagnosis combined with structured approaches to caregiving and careful use certain medications can make huge difference in behavior and progression of symptoms.
- A definite diagnosis can still not be confirmed until an autopsy is completed DLB is a 'probable' diagnosis or a 'possible' diagnosis, based on symptoms and progression.
- It was first seen and discovered by Dr. Lewy in 1912, but generally went undiagnosed or unrecognized until very recently.

***Other names for or diagnoses that are variants of Lewy body Dementia or share common characteristics:***

- Lewy body dementia (LBD) or Dementia with Lewy bodies (DLB)
- Lewy body disease (LBD)
- Diffuse Lewy body disease (DLBD)
- Cortical Lewy body disease (CLBD)
- Lewy body Variant of Alzheimer's (LBV)(LBVA)
- Parkinson's disease with dementia (PDD)

***Who is at Risk?***

- More men than women are diagnosed with DLB, at this time.
- Risk is higher, if there are close blood relatives with DLB, but a clear genetic link has not been identified at this time

***How Common Is It?***

- It is either the second most common or the third most common, depending on the source.
- When all variations are included, there are over 1.5 million people with DLB in the US.
- There are a large number of people who are misdiagnosed or undiagnosed, but are living with the symptoms of DLB.

***How Does It Progress?***

- Average length of life after symptoms appear is 5-7 years with a range of 2-20 years.
- It tends to progress from infrequent episodes to a more consistent and gradually worsening picture. Symptoms still vary in intensity and severity, but as the disease advances, they are typically present most of the time. First symptoms typically involve hallucinations, falls or movement problems, and some confusion about reality.
- By the middle of the disease, mobility skills are very impaired (a walker or even a wheelchair may be needed), functional skills are very limited (help is needed for almost all fine motor tasks), there are more problems with hallucinations and delusions, sensory intolerance (especially around the mouth, on the palms and fingers, soles of the feet, and in the genital region), and disturbances in sleep and wake patterns can be marked and challenging. Weight loss is common as is difficulty with swallowing, chewing, and speaking clearly and showing facial emotions clearly. By this time, it is common that falls have resulted in fractures and head wounds.
- By the end of the disease, the person will typically be bedbound or will need specialized seating in a reclining seating system. Rigidity and stiffness are very common and make movement and care very difficult for both the caregiver and the person with DLB. The person is able to move little, and requires major amounts of physical help for all care and engagement in preferred activities. The person may find touch uncomfortable and painful, even if it is delivered slowly and gently. The person typically has a very difficult time communicating. Speech is very soft and indistinct and often off target or repetitive in nature.

### ***How Does It Progress? (cont'd)***

- Death is typically a result of pneumonia or other infection, which the body cannot fight off even with the use of antibiotics. Pneumonia is typically caused by aspiration (food or liquids getting into the airway due to problems with eating or drinking and breathing regulation). Other infections can be localized (repeated UTIs (urinary tract infections), open pressure ulcers or wounds (caused by the inability to move or friction with repeated movements), skin injuries (when hitting a hard or sharp surfaces or skin exposure to urine or feces), or contractures (tightening and shortening of muscles that keep body parts closed together), the use of tubes or catheters (feeding tubes or urinary catheters). Still other infections can be or systemic, called sepsis, an infection in the blood stream. Other causes of death include malnutrition and dehydration, complications following falls (head injury or fractures), pulmonary emboli (clots that travel to the lungs due to prolonged immobility), or heart failure.

### ***What Basically is Happening?***

In this type of dementia, the nerve cells in outer layer of the brain have lumps of alpha-synuclein protein form inside the nerve center. These proteins cause the cells to have difficulty sending and receiving messages. Over time, they cause acetylcholine and other chemicals to be depleted resulting in problems with perception, thinking, and performing actions and movements. As the proteins spread throughout the cortex, symptoms worsen and cells begin to shrink and die.

The protein also occurs in the deep midbrain and the brain stem. There it affects more of the basic autonomic functions such as breathing, sleeping, heart rate, blood pressure, temperature regulation, and ability to fight infections.

It is important to note that some medications typically used in other dementias or in Parkinson's to help with hallucinations, behaviors, and sleep disturbances can cause rapid and very dangerous changes for someone with DLB (over 50% of those with DLB have this sensitivity)

### ***What are the Common Symptoms of DLB?***

Typical areas include: movement and performance problems, sensation disturbances, visual processing impairment, reasoning and thinking problems, emotional control problems, autonomic function problems. and sleep disturbances

- Falls – often on uneven surfaces, in tight spaces, with changing flooring, or with sudden direction changes – work-ups reveal no apparent cause for the fall – falls can often result in head, shoulder, hip, or back injuries due to lack of attempts to 'catch' or correct the fall – more often described as a 'timber' type fall than controlled or a 'trip' – shuffling gait or leaning to side often noted
- Episodes of immobility or rigidity – can't move when asked, very stiff – later mobility returns to normal levels
- Visual hallucinations – seeing things that are not real – most frequently the subjects are people, children, or animals, many are negative or unpleasant – more frequent at night than during the day (80% of people with LBD have recurrent hallucinations)
- Sleep disturbances – insomnia, night time wakefulness with agitation and emotional distress, nightmares that are 'real' to the person, acting out dreams rather than staying asleep
- Poor or problematic responses to neuroleptics/anti-psychotics typically used to treat hallucinations or delusions – can cause more anxiety or agitation, increased rigidity or inability to move, or sudden death. Drugs of most concern are: haloperidol (Haldol), risperidone (Resperidol), and quetiapine (Seraquel)

## ***What are the Common Symptoms of DLB? (cont'd)***

- Fluctuations in autonomic functions – sudden collapse (syncopal episodes), drops in blood pressure or heart rate, loss of urine control, constipation, sweats, changes in temperature, or inability to swallow – then full recovery
- Problems using fingers or hands, sometimes with high sensitivity – spills, awkwardness, complaints of touch or temperatures, holding fingers closed tightly or clenched in a fist, problems figuring out how to use utensils or tools
- Delusions – mis-interpretation of events, people's actions, or relationships – mis-understanding of reasons people are doing things or where people have gone or what they are saying, may have 'paranoid-like' tendencies
- Depression – emotions may be negative or hostile, or may seem 'flat' and apathetic
- Urgency incontinence – inability to wait to void, the sudden intense and frequent need to urinate is very common with DLB (not with Parkinson's or Alzheimer's) in early stages.

## ***Diagnostic Work-Up – What Should Be Done?***

*Consider seeking out a specialist in dementia evaluation, if symptoms are not typical for Parkinson's disease or Alzheimer's disease, as missed diagnosis is common*

- Complete physical and neurological examination
- Complete medical history and history of symptom development from the person but also family or care provider (in private setting)
- Neuro-psychological testing
- Functional abilities in attention, language, visual-spatial skills, memory and thinking/reasoning skills, fine and gross motor skills.
- Brain imaging (CT or MRI scans) – preferred possibly would be PET scans to determine chemical changes
- Blood tests, and other laboratory tests to rule out other possibilities

Probable DLB should be considered if:

There has been a change in thinking and reasoning (it is progressing) AND 2 of the following are noted:

- a. Fluctuating alertness and thinking/reasoning
- b. Repeated visual hallucinations
- c. Parkinson-like symptoms

Possible DLB, should be considered if there has been a change in cognition and ONE of the three symptoms are present.

Other symptoms to consider, would be REM sleep disturbances, problems with autonomic nervous system, delusions and episodic worsening memory or confusion (once other causes are ruled out).

## **Medications – Controversy and Challenges**

*Medications are frequently difficult to manage because of the combination of symptoms. Ones that might help with one symptom typically worsen others. Additionally, some are very dangerous for people with DLB. Seek out a skilled health care provider who will work with you to help manage the needs that develop over time. Be a strong advocate, ask about purpose, effects to expect, side effects to watch for, and indications of possible danger signs. It will be difficult at times to know if the results you are seeing are due to the progression of the illness or medication results or side effects.*

- **Thinking and Behavior Aid** - Because acetylcholine is depleted, acetylcholinesterase inhibitors (Aricept, Exelon, Razadyne) are usually recommended to try to help with alertness, thinking, memory, and they may reduce hallucinations. Possible negative side effects most commonly include nausea, vomiting, diarrhea, and possibly increased arousal (these may be short term).
- **Mobility and Movement Aid** - The use of Parkinsonian medications like carbidopa/levodopa (Sinemet) can sometimes help with the rigidity and movement problems, but it can also increase the frequency and intensity of delusions, hallucinations, or emotional outbursts.
- **Emotional Distress or Depression Aid** – Anti-depressants that are selective serotonin reuptake inhibitors (Ex: Celexa, Lexapro, Zoloft) are used to help depression or apathy is problematic. Possible negative side effects include drowsiness, dry mouth, nausea, trouble sleeping.
- **Hallucinations & Delusions Aids** – Because these symptoms can result in problematic behaviors of distress, anger, paranoia, frustration, fear, and anxiety, medications that reduce hallucinations or delusions are considered (ex: Haldol, Respiradol, or Seroquel). These medications can actually worsen behaviors for many people with DLB or may immobilize them or cause them to develop severe and rapid tardive dyskinesia.
- **Alternative Options to Manage Distress or Anxiety** – Two other options are being used to help with symptoms. One option is anticonvulsant medication (Depakote) and another is an antidepressant (trazadone) that has calming features that may help with tolerating care assistance or getting to sleep with fewer side effects.

## **What Should Be Done Routinely?**

- Complete durable healthcare and financial power of attorney decisions and paperwork
- Complete advance directive planning and financial planning
- Develop and use daily routines that include:
  - Exercise – aerobic, strengthening, coordination, and flexibility
  - Self-care – modify help as skills are lost
  - Leisure activities – make modifications as skills are lost
  - Work or productive activities – abilities may be lost early in the disease, use of time will need to be addressed
  - Rest times – breaks in the action, sleep will need to be structured in and additional caregiver may be needed at night to ensure that the primary caregiver gets rest when insomnia is problematic
  - Time away for the care partner
  - Time out of the home – with friends or neighbors when mobility is adequate
- Check out Safety issues with skilled health professionals (OTs or PTs) – modify the home for specific safety concerns that are identified
- Check out the need for rehabilitation for mobility and functional losses (OT, PT, Speech)

### ***What Should Be Done Routinely? (cont'd)***

- Continue familiar activities and groups (watching versus doing) – consider providing some education and training for others to help them in helping the person feel included and successful
- Look at care options and locations for possibilities as needs and abilities change
- Get counseling and support if mood and personality changes are affecting relationships and roles in the family and community

### ***Special Treatment Considerations:***

#### **Early Issues:**

- Give up arguing – go with the FLOW! – especially with hallucinations or delusions INSTEAD offer comfort and protection as needed AND try and figure out if there are any environmental cues that are triggering the behaviors or visual mis-understanding
- If the person ‘gets stuck’ – as long as they are not in danger, let them stay where they are, then consider re-approaching and asking for a goal oriented or automatic movement (“Let’s go get some juice.” or “Come help me.”, or give a very small specific direction to get the movement started (“pull your feet back...”)(place a flat palm on the person’s knee or shins). Stay calm and keep your voice relaxed.
- If the person has falls, consider using ‘partnered walking’, like old-fashioned strolling. This way you will be in place to help, but it will not feel like you are trying to take over or force movement. High risk areas tend to be outdoors, uneven surfaces or steps, close quarters (bathrooms or bedrooms), and crowded or busy spaces. A PT consult may be helpful for maintaining or improving mobility skills and coordination activities.
- Look at clothing, dishware, utensils, controls and consider modifications that require less dexterity or skill. An OT consult may be helpful in modifying the environment and tasks, so the person can still participate actively.
- If there are swallowing concerns. Talk with your health provider about modifying medications to limit ‘pills’. It may be possible to get some as powders, others as liquids, and some as capsules rather than pills. Also begin considering food items and their presentation. Serving meats that don’t require cutting into pieces, or careful chewing. Cutting sandwiches into wedges, or moving to more ‘finger’ options, use of mugs for soups rather than bowls, or use of straws for liquids with covered cups. A speech therapy or OT consult may be helpful to determine some options that may help.

#### **Middle Stage Issues:**

- Create daily routines and schedules that foster a balance of exercise and movement, quiet time and active time, slow and consistent transitions with multiple cues. Build environmental supports into the routines so that the person can complete personal care needs as they go from one place or activity to another.
- Limit fine motor demands in all areas. Simplify clothing, tools, tasks, activities, and expectations. Do only the parts of the tasks that the person cannot do. Staying as actively involved, as possible helps with night time wakefulness.
- Make sure all seating used by the person, has armrests that are stable, and that the seat height is equal to or greater than heel to knee height (so the person can come to stand more easily).
- Also consider a high-quality cushion for common seating (both the back and bottom of the seat) to reduce the risk of pressure ulcer formation.

### **Middle Stage Issues (cont'd):**

- Modified texture for foods and changes in drinks are frequently needed to help with safety, maintain calorie and protein levels. Typically, more frequent but smaller meals or snacks work better than traditional meals to get adequate amounts of food and fluid in. Also, thickened liquids might be recommended at this time to address swallowing/aspiration concerns. Supplements might be used to help, but should be offered between regular meals to increase the possibility that food will be eaten as well.
- When possible, the use of hand under hand techniques rather than dependent assistance is helpful, as it provides the person more information about what is being asked of them and helps them to use any remaining gross motor abilities, even though they have no fine motor skills.

### **Late Stage Issues:**

- Consider and explore the use of low dose acetaminophen on a regular schedule to help with possible 'pain' due to muscle discomfort, immobility, pressure areas, and joint stiffness combined with the inability to communicate needs verbally.
- Keep spaces warm and use light-weight and warm blankets.
- Keep one hand still, using a flat open palm on a shoulder or hip, while providing care with other hand.
- Keep action slow and controlled. Give information about what you are going to do. Then consider using limited conversation to distract the person with familiar and friendly comments OR be quiet, if that is their preference OR use favorite music at a low volume.
- Limit contact with the palms, soles of the feet, around the mouth and in the genital area. Make sure temperature of cloths and water is at a level that is OK for the person. Apply them to a less sensitive place prior to putting them in high-sensory areas.
- Use two people to give care – One to help reassure or monitor the person for safety and comfort, while the other performs necessary tasks or manages equipment or materials/supplies.
- Use bed bathing versus showering or whirlpools, if sensation is extreme and distressing.
- Do not routinely use palm mitts, or protectors, splints or foam palm supports, if there is a strong 'grasp reflex' or palm sensitivity due to increased probability that these devices will cause greater closure or cause more discomfort. Instead, use forearm pillow props to keep hands from contacting objects, use 'hand under hand' with firm pressure in palm when care is needed and consider the use hand sanitizer (without alcohol) to help with hand hygiene.

### ***Some Resources for specifically for Lewy Body:***

Lewy Body Dementia Association - [www.lewybodydementia.org](http://www.lewybodydementia.org)

Mayo Clinic - [www.mayoclinic.com/print/lewy-body-dementia](http://www.mayoclinic.com/print/lewy-body-dementia)

Family Caregiver Alliance - [www.caregiver.org](http://www.caregiver.org)

Comparing Alzheimer's, Parkinson's, & LBD -  
<http://www.primarypsychiatry.com/aspx/articledetail.aspx?articleid=2034>

Help Guide for Lewy Body - [www.helpguide.org/elder/lewy\\_body\\_disease.htm](http://www.helpguide.org/elder/lewy_body_disease.htm)

National Institute of Neurological Disorders & Stroke -  
[www.ninds.nih.gov/disorders/dementiawithlewybodies](http://www.ninds.nih.gov/disorders/dementiawithlewybodies)

### **Some Resources for specifically for Lewy Body (cont'd):**

Clinical trials DLB –

[www.clinicaltrials.gov/search/term=%22Dementia%20With%20Lewy%20Bodies%22](http://www.clinicaltrials.gov/search/term=%22Dementia%20With%20Lewy%20Bodies%22)

Alzheimer Research Forum - [www.alzforum.org](http://www.alzforum.org)

Webinar on LBD research- <http://www.alzforum.org/res/for/journal/detail.asp?liveID=175>

### **Books by families or people living with LBD out –**

*Living With Lewy's*; Empowering Today's Dementia Caregiver, by Amy and Gerald Throop is available now from Cando Books LLC

*Same Destination, Different Journey: Lewy Body Dementia: Our Journey* an e-book by Emma Haslegrave. Published in 2018 by Just Be Friendly Press, available on Amazon.