OBJECTIVES

After reading **Lewy Body Dementia**, the reader will be able to:

- Identify the characteristics of Lewy Body Disease.
- List medications that can cause unintended consequences.
- Describe several examples of treatment modalities.
- Apply preventative techniques for risk reduction.
- Identify community, medical and other resources.

AUDIENCE

This course is designed for all medical professionals who come in contact with persons who have been diagnosed with a form of dementia and may have difficult behavior. These patients may be seen at home with a caregiver, in doctors’ offices, hospitals, mental health settings, long-term care communities, or other settings.

INTRODUCTION

Dr. Lewy was a prominent German-born American neurologist. In 1912, Friedrich Heinrich Lewy first described these inclusion bodies named after him. He is best known for the discovery of the protein masses in brain biopsy samples, which are a characteristic indicator of Parkinson's disease and dementia with Lewy bodies.

The second most common form of dementia is Lewy Body. It is also called Lewy Body Dementia (LBD), Diffuse Lewy Body Disease, Lewy Body Disease, Senile Dementia of Lewy Type, Cortical Lewy Body Disease, Lewy Body Variant of Alzheimer's Disease or Parkinson's Disease Dementia. It is currently widely underdiagnosed and yet affects an estimated 1.3 million people (considerably more men than women) just in the United States. LBD usually occurs sporadically, in people with no known family
history of the disease. About 20% of persons with a dementia have Lewy Body Dementia. This is a progressive degenerative disease of the brain. It shares characteristics and clinically recognizable features with several other diseases, especially Alzheimer's and Parkinson's.

There are two types of LBD:

- Dementia with Lewy Bodies
- Parkinson's Disease Dementia

The earliest signs of these two diseases differ but reflect the same biological changes in the brain. Over time, people with dementia with Lewy bodies or Parkinson's disease dementia may develop similar symptoms. LBD patients will benefit from regularly scheduled visits with a neurologist who specializes in dementia and/or movement disorders. Memory disorder and movement disorder clinics are found all over the world. They are usually associated with a medical university or large hospital systems.

**CLINICAL DIAGNOSIS: PROBABLE OR POSSIBLE**

There are three core features and three suggestive features of Lewy Body Dementia. These features are use when determining if the clinical diagnosis of LBD is probable or possible.

A **probable LBD diagnosis** is determined if one of the following conditions is met:

- Dementia plus two or more core features
- Dementia plus one core feature and one or more suggestive features

A **possible LBD diagnosis** is determined if one of the following conditions is met:

- Dementia and one core feature
- Dementia and one or more suggestive features

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<th>Three Core Features of Lewy Body Dementia</th>
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<td>• Fluctuating cognition with pronounced variation in attention and alertness</td>
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<td>• Recurrent visual hallucinations (typically well-formed and detailed)</td>
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<td>• Spontaneous features of Parkinsonism</td>
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<tr>
<th>Three Suggestive Features of Lewy Body Dementia</th>
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<td>• REM sleep behavior disorder</td>
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<td>• Severe neuroleptic sensitivity</td>
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<td>• Low dopamine transporter uptake in the basal ganglia demonstrated by SPECT or PET imaging</td>
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**WHY IS LEWY BODY DEMENTIA SO IMPORTANT?**

Frequently misdiagnosed as Alzheimer’s or Parkinson’s disease or a psychiatric disorder, Lewy body dementia poses a diagnostic challenge. LBD’s symptoms often overlap with these diseases. LBD victims are losing cognitive ground. They seem to be less prone to the short-term memory loss associated with Alzheimer’s than to problems with executive function. They struggle to handle complex tasks like grocery shopping. They also may develop visuospatial problems and find it hard to navigate or perceive distances, so that they lose their way in familiar settings or misjudge distances and fall. Lewy body dementia seems to progress more rapidly than Alzheimer’s; most LBD patients don’t live as long. Certain antipsychotics and stimulants, and some Parkinson’s and Alzheimer’s medications, may make life easier for patients and their caregivers for a while.

According to Dr. James Galvin, a neurologist who specializes in LBD at NYU Langone Medical Center, “There’s no way to repair the damage that’s been done” to the brain. “All you’re doing is slowing down the symptoms’ progression without changing the underlying disease.”

**SYMPTOMS**

Some of the most common symptoms include decreased alertness and attention. Other symptoms may include:

- Frequent drowsiness
- Lethargy
- Lengthy periods of time spent staring into space
- Disrupted speech patterns
- Recurrent visual hallucinations
- Depression

Another common symptom is orthostatic hypotension or low blood pressure. This can cause dizziness and fainting. If there are indications and signs of stroke or vascular dementia, the diagnosis would then usually rule out the likelihood of LBD.

**BEHAVIORS PRESENTED BY LBD**

- **Dementia:** Confusion, loss of memory, and poor judgment.

- **Hallucinations:** Hallucinations may be auditory (hearing sounds), olfactory (smelling or tasting something) or tactile (feeling or touching something that is not there).

- **Cognitive Fluctuations:** The patient may converse normally one day and be mute and unable to speak the next day. There are also fluctuations in attention, alertness and wakefulness.
**Parkinson's-Like Symptoms:** Rigidity or stiffness, shuffling gait, tremor, slowness of movement (Bradykinesia), mask-like facial expression.

**Rapid Eye Movement (REM) Sleep Behavior Disorder:** Vivid dreaming, talking in one's sleep, and excessive movement while asleep; may include hitting a bed partner. Because of the sleep disturbances, excessive daytime drowsiness may appear years before DLB is diagnosed. About 50% of patients have this symptom.

**Complex Mental Activities:** More problems with multitasking, problem solving, and analytical thinking, than with memory.

**ALZHEIMER’S AND LEWY BODY RISK FACTORS**

There is a frequent and extensive overlap, both clinically and pathologically, between dementia with Lewy bodies and Alzheimer’s disease. The two diseases share several genetic and environmental risk factors. As with Alzheimer's, LBD risk is heightened with inheritance of the ε4 allele of the apolipoprotein E (APOE). This increased risk is related to the apolipoprotein E (APOE) gene found on chromosome 19. APOE contains the instructions for making a protein that helps carry cholesterol and other types of fat in the bloodstream. APOE comes in several different forms, or alleles. Three forms occur most frequently:

- **APOE ε2** is relatively rare and may provide some protection against the disease. If Alzheimer's disease occurs in a person with this allele, it develops later in life than it would in someone with the APOE ε4 gene.
- **APOE ε3**, the most common allele, is believed to play a neutral role in the disease—neither decreasing nor increasing risk.
- **APOE ε4** is present in about 25 to 30 percent of the population and in about 40 percent of all people with late-onset Alzheimer's. People who develop Alzheimer's are more likely to have an APOE ε4 allele than people who do not develop the disease.

There are also increased inflammatory states associated with increased disease risk. Pathological and experimental work has implicated the involvement of activated microglia (a type of neuronal support cell or neuroglia) occurring in the central nervous system. Neuro-inflammatory processes may be the common link driving progression in both diseases and explaining the frequent overlap between the two diseases.

**WHAT IS HAPPENING IN NURSING HOMES?**

When a person with LBD acts out - and perhaps he is acting out from his (very real to him) dreams or believes people are out to get him - the first steps that professional caregivers can do is to observe and evaluate for physical ailments that may be triggering the behavior. Could he have a urinary tract infection? Is he arthritic and in pain? When was the last time his teeth/mouth has been checked for sores, infected teeth or other oral concerns? Has he fallen and broke a bone? Is there a fecal impaction, decubitus (pressure) ulcers, or an upper respiratory infection like pneumonia? Have there been any changes in environment, roommate or medications lately? All of these could have provoked anger and loss of control for the person with LBD. Sometimes we have to read what the problem is through their body language.
A thorough dementia diagnostic evaluation should include:

- Physical and neurological examinations
- Patient and family interviews
- A detailed lifestyle outline
- Family and medical history
- Neuro-psychological tests
- Mental status tests

The following medications may cause worsening of the patient’s condition, increased confusion, and/or unintended consequences:

- Antidepressants
- Benzodiazepines
- Diazepam
- Lorazepam
- Antipsychotic medications like haloperidol (Haldol)
- Risperidone
- Anticholinergics and dimenhydrinate (Advil PM, Sominex, Spiriva, Dramamine)
- Diphenhydramine (Benadryl)
- Amantadine (An antiviral medication used to prevent or treat certain influenza infections and also given as an adjunct treatment for Parkinson's disease)
- Dopamine agonists (L-dopa is the most widely used therapy for symptomatic management in Parkinson’s Disease to help relieve symptoms, but it might increase confusion, delusions or hallucinations.)

Quetiapine (Seroquel) is preferred by some LBD experts. Be aware and exercise caution when surgical anesthetics have to be used. It is important to meet with an anesthesiologist in advance of any surgery to discuss medication sensitivities and risks unique to LBD.

According to the Lewy Body Dementia Association, up to 50% of patients with LBD who are treated with any antipsychotic medication may experience severe neuroleptic sensitivity, such as worsening cognition, heavy sedation, increased or possibly irreversible Parkinsonism, or symptoms resembling neuroleptic malignant syndrome (NMS). NMS causes severe fever, muscle rigidity and breakdown that can lead to kidney failure, which can be fatal.

**AVAILABLE TREATMENTS**

Since LBD is a multi-system disease the management of the disease will require a comprehensive treatment approach. This means that physicians and professionals from different specialties (e.g. neurologist, primary care, pharmacist, physical/occupational therapy, social worker) work as a team to collaborate to provide optimum treatment of each symptom without worsening other LBD symptoms. This
can be accomplished in the home, through a home health agency, an adult day program, a rehabilitation center or in a long-term care environment.

**BENEFICIAL THERAPEUTIC OPTIONS**

**Physical therapy** can help with movement problems through cardiovascular, strengthening, and flexibility exercises as well as gait training and general physical fitness programs.

**Speech therapy** may help with low voice volume, voice projection, poor speaking ability, and swallowing issues.

**Occupational therapy** can help promote independence and identify problems with everyday activities, such as eating and bathing.

**Music and art therapy** may provide meaningful activities that can reduce anxiety and improve well-being.

**Mental health counselors** can help persons with LBD, their families, and caregivers learn how to manage difficult emotions and behaviors and plan for the future.

**REDUCING THE RISK**

Researchers have found that some forms of dementia may be the result of factors that we control: our diet, activity level, the amount of sleep we get, how we manage stress, and other life situations. Other factors we control are: smoking (any kind); too much alcohol (more than three drinks a day); excessive use of prescription and over-the-counter drugs; and engaging in risky and/or unhealthy behaviors (e.g. contact sports, auto racing, junk food, drugs). Just as you can help reduce your chances of having heart attacks, strokes, diabetes, or even cancer by simple lifestyle changes, here are five areas of life where lifestyle changes may decrease your chances of developing a form of dementia.

**SLEEPING**

The body needs sleep. Without sleep, your body cannot repair the damage from the day’s activities. Too little sleep will result in mood changes, poor judgment, and potentially dangerous situations (e.g. operating machinery, driving). Anyone over the age of 40 should have at least seven hours of sleep. This will ensure that you think clearly and calmly, and will allow you to do your best. Routine is the key to sleep.

**EATING**

We are all aware of the dangers of too much sugar, too much salt, high-fat foods, processed foods, etc. Scientists have found that too much sugar in the brain can actually speed up the aging process. To get healthy and stay healthy, a person must eat healthy for life. An easy way to remember is to “eat the rainbow,” that is, every day eat something red, something green, something orange, something yellow, and so on. The more colors and more variety you have, the better your health will be. Leafy greens, beans and legumes, all kinds of berries, and seeds can help round out a healthy diet and nourish your brain.
**EXERCISE AND ACTIVITY**

On a continual basis, we are bombarded with TV and newspaper reports about the “obesity epidemic” in this country. Just like with coronary diseases and other medical conditions, too much weight causes your body to work harder to deliver blood and nutrients to your brain. It is essential that exercise be a part of your daily routine. One of the most effective forms of exercise known involves only 20-30 minutes of your daily time: walking. It is just as important to exercise your brain. “Use it or lose it” is more than just a phrase. Play some brain games today!

**RELAXATION**

How do you relax? This is a hard question for many folks. It seems like the tasks never end and the constant juggling to take care of it all can eventually break even the strongest person. Can you get a massage once a month? Do you hear the casino calling your lucky numbers? Love to go shopping? Can you take a few days to travel to visit family? Find a way to relax that works for you and make time for it.

**SOCIALIZING**

For your mental, emotional, and psychological health, the more outside contacts you have, the better your overall health. Socializing helps prevent depression and keeps you mentally stimulated. Fraternal and social clubs (e.g. Veterans organizations, alumni groups, bowling leagues, church activities) are important ways for us to remain connected. Going out with a friend or having a girls’ night is another way to allow yourself to enjoy life, interact with friends, and take a much needed break.

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**Did You Know?**

- Kelsey Grammer’s lead character as mayor of Chicago, Tom Kane, in the television series *Boss*, suffers from early-stage Lewy body dementia.
- In the Japanese anime series *Ghost Hound*, psychiatrist Atsushi Hirata emails an MRI scan image of a brain to colleague, neurologist Reika Ōtori, who initially diagnoses the brain in the image as showing signs of Lewy body dementia. He shocks her by saying the MRI is his own brain, and recent apparitions and altered states of consciousness experienced by him may be related to the depicted condition of his brain.

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**ADVANCING DISEASE KNOWLEDGE**

Only a brain autopsy at the time of death can provide confirmation that an individual suffered from a form of dementia. The intent of the brain bank program is to study brains of persons clinically diagnosed with a dementia and provide tissue for research after their deaths.
Families obtain significant benefits from the brain bank program. The brain autopsy will give a final confirmation of the disease. This brain donation can be involved in research that will help future victims of LBD and other forms of dementia. The information will be a part of the family medical history which can prove invaluable.

Brain donation for research is not a widely publicized subject, so many physicians and pathologists are not familiar with brain donation. Working with pathologists at your local hospitals and identifying the professionals in your area who are sensitive to the need for brain donation can greatly facilitate the donation process. Brain donation does not conflict with most religious perspectives and will not interfere with an open casket or other traditional funeral arrangements.

**BRAIN BANK PROGRAMS**

- The Florida Brain Bank:  [http://elderaffairs.state.fl.us/doea/BrainBank/](http://elderaffairs.state.fl.us/doea/BrainBank/)

**RESOURCES**

There are many support programs available through adult day programs and community centers. The National Area Agency on Aging has offices that serve every county in the U.S. Meals on Wheels programs, Veterans outreach organizations, parks and recreation departments and other local resources can be accessed by referrals from doctors and therapists. These kinds of programs are essential to keeping the person with LBD engaged in daily activities, enable professionals to do ongoing assessments, and to give the primary caregiver(s) much needed respite.

The Social Security Administration (SSA) has a compassionate allowance program in which workers diagnosed with dementia with Lewy bodies can qualify for Social Security disability benefits. Call the SSA at 800-722-1213 or visit [http://www.ssa.gov/](http://www.ssa.gov/).

- Family Caregiver Alliance:  [http://caregiver.org/](http://caregiver.org/)
- National Association of Area Agencies on Aging:  [http://www.n4a.org/index.cfm](http://www.n4a.org/index.cfm)
- The Michael J. Fox Foundation for Parkinson’s Research:  [https://www.michaeljfox.org/](https://www.michaeljfox.org/)
1) Which is NOT another name for Lewy Body Dementia?
   A. Diffuse Lewy Body Disease
   B. Senile Dementia of the Lewy Type
   C. Cortical Lewy Body Disease
   D. Lewy Body of the Cortex

2) Over time, people with Dementia with Lewy Bodies or _____ disease dementia may develop similar symptoms.
   A. Muscular Dystrophy
   B. Parkinson’s
   C. ALS
   D. Down’s Syndrome

3) Various symptoms of LBD include drowsiness, disrupted speech patterns, hallucinations, and _____.
   A. Low blood pressure
   B. Frequent urination
   C. Constipation
   D. High blood pressure

4) People with the highest risk of developing dementia carry the _____ gene.
   A. APOE
   B. APOE ε2
   C. APOE ε4
   D. APOE ε7

5) Hallucinations with LBD patients may be all of the following EXCEPT:
   A. Auditory
   B. Olfactory
   C. Tactile
   D. Erogenous
6) When getting a thorough dementia evaluation, the exams should include a neurological exam, lifestyle outline, family history and _____.
   A. Mental status exam
   B. Overseas trips
   C. Driving evaluation
   D. Education level

7) The drug _____ is preferred by some LBD experts.
   A. Diazepam
   B. Seroquel
   C. Lorazepam
   D. Risperidone

8) Which therapy would not necessarily help a LBD patient?
   A. Physical therapy
   B. Speech therapy
   C. Hydrotherapy
   D. Art therapy

9) An easy way to remember how eating can help with prevention is to:
   A. Eat the rainbow
   B. Eat everything on your plate
   C. Eat when hungry
   D. Eat three times per day

10) Only a _____ can provide confirmation that a person had LBD.
    A. Doctor’s evaluation
    B. Neurologist’s confirmation
    C. Brain autopsy
    D. Toxicology test
Your opinion is important to us. Please answer the following questions by circling the response that best represents your experience.

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<th>COURSE OBJECTIVES &amp; CONTENT</th>
<th>Strongly Agree</th>
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<td>2. The content was up to date.</td>
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<td>2. The number of credit hours was appropriate for the content.</td>
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<td>4. The teaching/learning methods, strategies, and slides were effective in helping me learn.</td>
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<td>8. The material was relevant to my professional development.</td>
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<td>9. Overall, I am pleased with this activity and would recommend it to others.</td>
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<td>10. The content was presented free of commercial bias. *</td>
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<td>11. Did the material presented increase your knowledge and/or understanding of this topic? *</td>
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* If you responded “No” to question 10, please explain why:

_________________________________________________________________________

_________________________________________________________________________

* If you answered “Yes” to question 11, what change do you intend to make?

_________________________________________________________________________

_________________________________________________________________________

What barrier, if any, may prevent you from implementing what you learned?

_________________________________________________________________________

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Cite one new piece of information you learned from this activity:

_________________________________________________________________________

_________________________________________________________________________

Additional comments/suggestions:

_________________________________________________________________________

_________________________________________________________________________

With my signature I confirm that I am the person who completed this independent educational activity by reading the material and completing this self evaluation.

Signature _________________________________ Date: _________________________
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Take Lewy Body Dementia Online

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Have you registered with us before?  ____ Yes     ______  No

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