

2023 SUMMER INSIGHTS

# Lewy Body Dementia

from the  
Department of Neurological Sciences

## Welcome to the Inaugural Edition of the Lewy Body Dementia (LBD) Newsletter!

In 2020, we received philanthropy support from a grateful patient's family for a UNMC/Nebraska Medicine Lewy Body Dementia Initiative to enhance clinical care and support, research, and education. As part of this initiative, we have developed a specialized LBD Clinic to focus on the needs of our LBD patients, their families, and caregivers provided by our LBD Experts. Our LBD Clinic also allows for additional scheduling with other providers like our Social Worker, Nutrition Therapist, and Psychiatry to avoid our patients making multiple clinic visits, which often can be time consuming. We also work closely with physical therapy, speech therapy, occupational therapy, and palliative care to assure our patients, families, and caregivers have access to all necessary disciplines to enhance the quality of their lives.

We have started a monthly Lewy Body Dementia Support and Wellness Group that meets on the third Monday from 9:30 a.m. – 11 a.m. at Heartland Neurological Therapy and Wellness Center, 2546 River Road Drive, Building C, Waterloo, NE. We also will be having our "Lewy Body Dementia Initiative Inaugural Conference" for patients and their families/caregivers on Wednesday, September 27, 2023, from 8 a.m. – 3 p.m. at the Scott Conference Center, 6450 Pine Street, Omaha, NE. The conference will provide a wonderful opportunity for all people on the LBD journey to network, attain education, and provide support. For questions or to obtain registration information and agenda, please email [unmcneuroconf@unmc.edu](mailto:unmcneuroconf@unmc.edu). All LBD events are FREE to attend, however, we do request RSVP to ensure adequate seating and refreshments.



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# The Lewy Body Dementias

by Daniel L. Murman, MD, MS, FAAN, Director, Behavioral and Geriatric Neurology Program; Vice Chair, Clinical and Translational Research; Professor, Department of Neurological Sciences

Where does the name Lewy body come from and what are “cortical” Lewy bodies?

The Lewy body disorders are named after Dr. Friedrich Lewy, who discovered abnormal nerve cell inclusions in the autopsied brains of patients who died from Parkinson’s disease (PD). These inclusions were found in the motor control parts of the brain (i.e., basal ganglia nuclei, especially the substantia nigra). Dr. Lewy described these inclusions starting in the 1920’s and subsequently these abnormal inclusions were called “Lewy bodies.”

In the 1960s, “cortical” Lewy bodies were discovered in patients with PD motor symptoms and features of dementia and psychiatric symptoms. These cortical Lewy bodies were composed of the same aggregated protein (i.e., alpha synuclein) seen in basal ganglia Lewy bodies, but they had a different appearance and distribution. Cortical Lewy bodies are found in the emotional parts of the brain (i.e., limbic system) and the thinking parts of the brain (i.e., cerebral cortex). Cortical Lewy bodies are associated with the changes in thinking and psychiatric symptoms seen in patients with one of the Lewy Body Dementias (i.e., PD with Dementia abbreviated PDD and Dementia with Lewy Bodies abbreviated DLB). Thus, Lewy bodies found in the brain at autopsy have helped us define and understand PD and the Lewy Body Dementias.

## What does the term dementia mean and what is the difference between PDD and DLB?

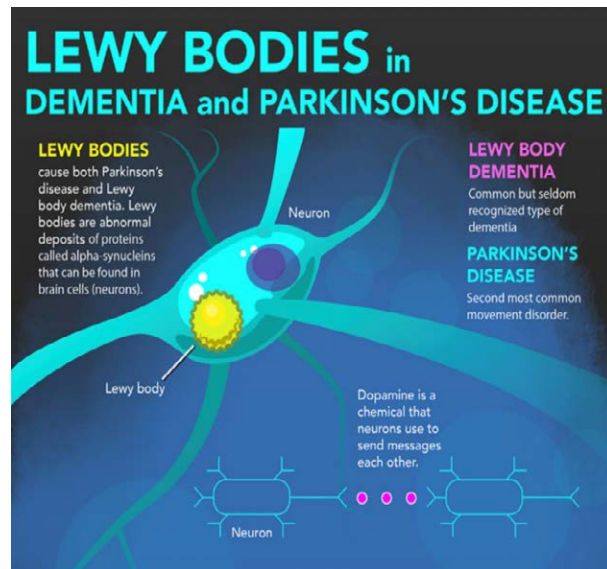
Dementia is defined as a decline in memory and thinking that is severe enough to limit a person’s ability to do every activity independently, such as driving, handling finances, shopping, cooking, and taking medications. Dementia can be caused by many conditions, including cortical Lewy bodies, and can be classified as mild, moderate, and severe. The main distinction between PDD or DLB is the timing of the dementia symptoms in relation to the timing of motor features of parkinsonism (i.e.,

stiffness/rigidity, slowness/bradykinesia, and tremor). In patients with PDD, motor symptoms appear first and typically for many years and then later a patient develops dementia symptoms. In patients with DLB, the dementia symptoms and the motor symptoms of parkinsonism develop together, or the dementia symptoms precede the motor symptoms.

## What are the symptoms and features of the Lewy Body Dementias? The clinical features of PDD

and DLB are very similar. Both conditions cause some combination of motor features of parkinsonism, including bradykinesia, rigidity, tremor, and eventually poor postural balance. The dementia symptoms can include problems with executive cognitive function (i.e., planning, multitasking, decision making), memory (i.e., retrieving information you have learned), visual spatial abilities (i.e., decoding complex aspects of what you see), and language (i.e., coming up with names). Fluctuations in thinking are very common in patients with PDD and DLB. Frequently patients have increased problems with thinking and confusion in the evening. This is where the term “sun downing” comes from. Patients with Lewy Body Dementia commonly have visual hallucinations, delusions, and are more likely to have dream enactment behaviors called REM Sleep Behavior Disorder (RBD). Patients with Lewy Body Dementia are at increased risk of acute confusion called delirium in the setting of hospitalizations, surgery, and medical illness.

**What treatments are available for Lewy Body Dementia symptoms?** The dementia symptoms of PDD and DLB can be



improved with a group of oral medications called cholinesterase inhibitors. The brand and generic drug names of this drug class include Exelon/rivastigmine, Aricept/donepezil and Razadyne/galantamine. These medications increase a brain chemical called acetylcholine and can help improve memory, attention, and everyday function and can decrease the severity of psychiatric symptoms such as hallucinations and delusions in some patients. Side effects can occur and include nausea, diarrhea and a runny nose. For patients with problematic visual hallucinations and delusions, we first try to adjust the PD medications that increase dopamine and are used to improve motor symptoms. The next option is to consider adding Nuplazid (pimavanserin), which is a medication that is FDA-approved for treating hallucinations in patients with PD. Problematic symptoms of dream enactment during sleep (RBD) can be treated with the over-the-counter medication melatonin or the prescription medication clonazepam/Klonopin.



# Social Work Role in the Outpatient Neurology Clinic

Sometimes when I meet with patients and families in clinic or call them on the phone, they seem surprised that a social worker is meeting with them or reaching out. You may be wondering, “Why would I need to talk with a social worker?”

A medical social worker in an outpatient clinic is a member of your healthcare team who can help address a variety of things that may be impacted by your health. In our neurology clinic, I reach out to patients and families to see how I can support you as you are navigating Parkinson’s Disease. Some of the ways that I do this include:

- Providing information and a connection to community resources for basic needs (i.e., financial concerns, transportation)
- Providing education and direction on Advance Directives
- Talking to people about disability benefits if you are unable to continue working
- Providing information and a connection to resources that can help with care needs in the home and/or respite care. As part of that, providing information on what programs or insurance coverage may (or may not) help with the cost of care

- Helping people adjust to an illness such as Parkinson’s Disease and discussing the ways it can affect patients and families. Helping people to develop coping strategies that can help with stress.
- Addressing long-term care needs and exploring care options both in the home and in the community
- Providing support to caregivers and discussing ways to care for both you and your loved one

If you feel that you could benefit from talking with a social worker, please let your healthcare provider know. You are not alone!



Colleen Hoarty, LCSW  
Medical Social Worker  
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# Strategies to Increase Calorie Intake



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Changes with Lewy Body Dementia (LBD) can affect how much you eat and can lead to eating less than you usually do.

Having a lower appetite, losing the ability to smell and taste food, feeling nauseous, sleeping more during the day, difficulty chewing and swallowing, and problems with the GI system such as constipation can all impact how much you eat. This can then contribute to weight loss, muscle loss, malnutrition, decreased energy levels, and missing out on key nutrients your body needs.

If you notice unintentional weight loss, it is especially important to use strategies to increase your calorie intake and support the nutrition and energy your body needs. Many people with LBD have a higher metabolism where the body is burning more calories than it used to. This would be another reason to increase the number of calories that you consume.

## The following ideas can be used to add more calories to your daily intake:

### Have more frequent meals and snacks:

- Create a schedule to eat 3 meals and 3 snacks between meals.
- Have something every 2-3 hours.
- Eat larger meals when your appetite is better. Appetite is generally the greatest in the morning.

### Add calorie-dense foods:

- Cook with milk instead of water when making hot cocoa, hot cereal, and pudding.
- Mix dried fruit, nuts, granola, honey, or dry cereal with yogurt and hot cereal.
- Add nuts and seeds to salads, pasta dishes, cereals, yogurt, and ice cream.
- Use sauces and gravies on meats, potatoes, vegetables, and noodles.
- Make casseroles with a soup or cream base.

### Pick out protein foods:

- Add beans and lentils to salads, soups, and casseroles.
- Include seafood, chicken, turkey, beef, and pork in casseroles, soups, or as the entrée.
- Enjoy cottage cheese or yogurt.
- Have spoonfuls of peanut butter or add to crackers, bread, waffles, apples, bananas, and celery sticks.

### Add fats to meals and snacks:

- Drizzle olive oil over noodles and rice after cooked.
- Cook eggs, vegetables, and meats in pan with oil or butter.
- Add avocado or guacamole to sandwiches, salads, burritos, egg scrambles, and smoothies.
- Make a meat or egg salad sandwich with extra mayonnaise.

### Drink liquids that contain calories:

- Drink milk, chocolate milk, and soy milk.
- Have smoothies with high calorie ingredients added such as heavy whipping cream, coconut cream, oils, peanut butter, cream cheese, avocado, and honey.
- Include ready-to-drink shakes such as Ensure®, Boost®, Carnation Breakfast Essentials®, Orgain®, Bolthouse Farms®, and many other brands. Look for varieties that have the highest number of calories.
- Drink fruit juice, vegetable juice, sports drinks, Naked® juices, and lemonade.





## Maintaining Brain Health

As we age, most of us will find that our brain, just like the rest of our body, loses some of its mental agility.

“The speed at which you process information, as well as your recall ability, begins to decline starting at about age 40,” says Daniel Murman, MD, Nebraska Medicine neurologist.

“The brain is much like other parts of your body, if you don’t use it, you will lose it.”

Participating in a variety of activities, which activates different neuronal pathways in the brain, will help improve the performance of your brain as you age. Every time you repeat an activity, you strengthen brain cells and reinforce the connections between them.

In fact, “recent studies show that regular participation in healthy lifestyle activities can help delay the onset of dementia by up to five years and may slow the speed that Alzheimer’s disease symptoms progress,” Dr. Murman says. Dementia refers to declines in memory and thinking that are

severe enough to interfere with everyday activities such as driving, doing finances, shopping or cooking.

By practicing these healthy lifestyle choices, you can promote brain health as you age.

### 1. Mental activity

Staying active mentally not only keeps nerve cell connections strong but may create new nerve cells. Practice things like reading, playing cards, puzzles, computer-based games, writing, researching or playing an instrument. “Different activities activate different areas of the brain,” says Dr. Murman. “Do things you enjoy. Even things like completing chores or cooking that activate the brain are good brain-building activities.” On the other end of the spectrum, activities like watching TV, unless you are actively engaged, are not going to help strengthen the brain.



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## 2. Physical exercise

Physical exercise promotes good blood flow to the brain and promotes brain health. “Just like exercise activates different muscles, it also reinforces different brain circuits,” explains Dr. Murman. “Try to reinforce activities that you will use in everyday life to help you with activities of daily living.”

## 3. Healthy diet

A diet high in fruits and vegetables, which contain antioxidants, may provide protective benefits that promote brain health, whereas a diet high in saturated fats and cholesterol, may do the opposite.

Researchers have found that a combination of the Mediterranean and Dietary Approaches to Stop Hypertension (DASH) diets, called the Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet, has the largest impact on building brain health. The MIND diet promotes eating 10 brain-healthy foods that include leafy green vegetables, other vegetables, berries, beans and legumes, nuts, whole grains, fish, poultry, olive oil and wine in moderation. The diet recommends avoiding five foods that have shown to be toxic to the brain. These include red meats, fried or fast foods, pastries or sweets, butter and cheese.

## 4. Socially engaged and positive emotional health

Staying socially active may be good for the brain by reducing stress levels and maintaining healthy connections among brain cells. Maintain an active social life with friends and family and participate in a variety of social activities like sports, dancing, musical events and other cultural activities.

## 5. Sleep

Sleep is very restorative to the brain and body. “If the benefits of sleep were sold as a drug, we’d all be taking it,” says Dr. Murman.

When you sleep, the brain stores new information and gets rid of toxic waste. Nerve cells communicate and reorganize, which supports healthy brain function. The body repairs cells, restores energy and releases molecules like hormones and proteins.

Unfortunately, the quality of your sleep often declines with age. If you find yourself very tired during the day and never feel like you are getting a good night’s sleep, you should be evaluated for a treatable sleep disorder, such as sleep apnea, recommends Dr. Murman. Sleep apnea can be detrimental to your brain health and may increase your risk of Alzheimer’s among other health problems like stroke and heart disease.

## 6. Avoid toxins to the brain

There are also things that can be detrimental to brain health such as excessive alcohol or drug use. Frequent and excessive use can damage memory circuits and accelerate the decline in mental aging, says Dr. Murman. Heart disease risk factors such as high blood pressure, high cholesterol, smoking, diabetes and obesity are also associated with a higher prevalence of dementia.

“Dementia is the sixth leading cause of death in the United States and a disease that people over 50 fear the most,” says Dr. Murman. “While medications have failed to slow the progression of conditions like Alzheimer’s disease, there is growing evidence that you can significantly reduce your risk by building your brain health.”

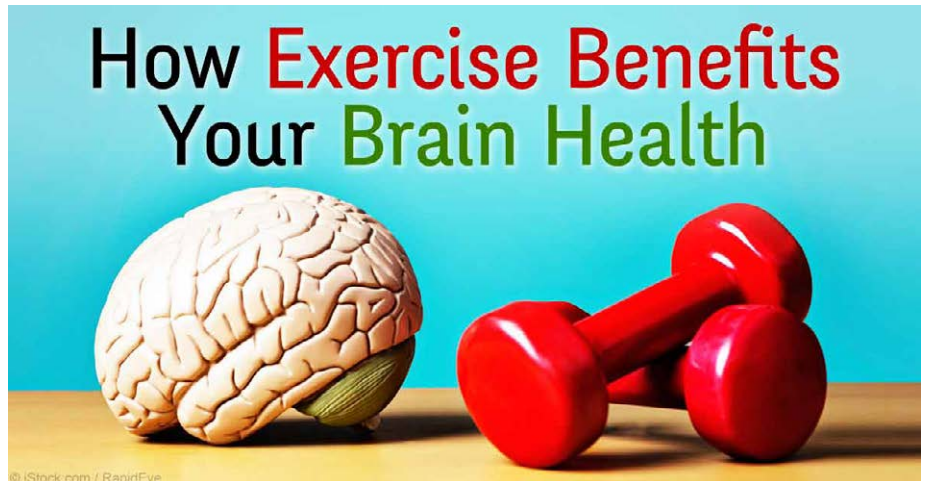


# Exercise is Medicine

Exercise is important for everyone. For an individual with Lewy Body Dementia, it is vital! Exercise is a key element to maintaining balance, functional mobility, and daily activities.

Exercise may have a neuroprotective effect, as well as improve neuroplasticity. In the brain, dopamine, which plays a role in starting movement, functions as a neurotransmitter. A neurotransmitter is a chemical released by nerve cells to send signals to other nerve cells. Exercise improves dopamine efficiency by modifying areas of the brain where dopamine signals are received. Exercise protects nerve cells that are at risk for damage, degeneration, or cell death. Another benefit is improvement in neuroplasticity—the brain’s ability to discover new nerve cell connections. In other words, exercise helps the body and brain find new ways to move.

Any level of physical activity is beneficial; however, studies show that increasing physical activity to at least 2.5 hours/week can slow decline in quality of life. Exercise improves strength, gait, balance, tremor, flexibility, grip strength, motor coordination, and endurance. It is important to include a combination of aerobic exercise to improve fitness, walking to practice gait, and resistance training to strengthen your muscles. There are many forms of exercise you may find to participate in: biking, running, Tai Chi, Yoga, Pilates, dance, weight training, non-contact boxing, group classes for Parkinson’s disease, or physical therapy to learn a focused program specific to your needs. It is beneficial to perform random practice with activities. This may



include changing the speed of movement, the direction, or varying the activity. Increase the intensity of your exercise for as long as you can and as often as you can.

Choosing to exercise gives you an active role in the management of your symptoms associated with Parkinson’s disease. In addition to the already mentioned benefits, exercise can positively affect mood and self-confidence, bone health, cognitive function, sleep, digestion and constipation, fatigue, rigidity and stiffness, and fine motor skills. The best way to see benefit from exercise is to exercise on a consistent basis. It is important to make exercise part of your regular routine. Sometimes it is helpful to make yourself an “appointment” for exercise. Put it on your calendar and make it something you commit to, just like you would a doctor’s appointment. When taking your medications, remember that exercise is medicine!



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If you have any news or upcoming events that you would like featured in the next edition of the *UNMC Lewy Body Dementia* newsletter, please send the information to [sallie.weathers@unmc.edu](mailto:sallie.weathers@unmc.edu)



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