My name is (speaker’s name here) and I’d like to thank you for coming today to learn about Lewy body dementia or LBD.

While this is a disease that most people have never heard of, LBD is actually the second most common form of progressive dementia. Up until about 10 years ago, even many neurologists were unfamiliar with it.

(SPEAKER: Lewy is pronounced LOO-wee, which sounds exactly like the name Louie, as in Louie Armstrong, the famous jazz trumpet player.)
This talk will cover the basics about LBD. I will talk about what LBD is and how it is different from other conditions like Alzheimer’s and Parkinson’s disease.

I will now go over LBD’s symptoms and how it is diagnosed and treated. Then I will talk a little about the Lewy Body Dementia Association and what you can do to raise awareness of LBD.

First, let me tell you a bit about dementia.
Dementia is not a single disease – it is actually a clinical syndrome (or a collection of symptoms) with many different potential causes. It means that a person is no longer able to independently manage aspects of their everyday lives, such as their finances, medications, personal hygiene, or household tasks due to a significant decline in their ability to think and reason.

Dementia affects a person’s abilities in more than one cognitive area such as

- **Memory** – the ability to recall what has been learned or experienced
- **Language** – the ability to understand words and express oneself with words
- **Judgment** – the ability to form sound opinions or make good decisions
- **Executive function** – the ability to plan, solve problems and understand abstract concepts
- **Visuospatial** function– understanding how items or places are physically related to each other in space
- **Attention** – the ability to mentally focus on something, such as someone talking or one’s surroundings.
While most of us are familiar with Alzheimer’s disease, dementia can have many other causes. For example, some medical conditions, including vitamin B12 deficiency and thyroid disease, can cause dementia symptoms. These conditions can be treated with medication, and the dementia symptoms can be reversed, returning a person to their usual mental abilities.

But, the most common forms of dementia are incurable and progressive – meaning that they get worse over time.

Alzheimer’s disease is the cause of approximately 50-70% of all dementia cases and features prominent memory problems, plus changes in thinking and behavior. It generally affects people over the age of 60, but a small percentage of people develop Alzheimer’s at a younger age. Alzheimer’s is more common in women.

Lewy body dementias (or LBD) affect thinking, movement, behavior, sleep and also automated bodily functions, like blood pressure and digestion. The term LBD refers to two related clinical diagnoses, which we will talk about in a few moments. Like Alzheimer’s, LBD predominantly affects adults over the age of 60, though a small percentage of people are being diagnosed with LBD in their 40’s and 50’s. LBD is slightly more common in men than in women.

We will use the term Lewy body dementia or LBD as an umbrella term today to include both clinical diagnoses. The two forms of LBD start with different presenting symptoms, but over time progress to very similar combinations of symptoms. One of those two diagnoses is formally named “dementia with Lewy bodies” and is the 2nd most common cause of progressive dementia. Research shows that it accounts for an estimated 15-35% of all dementia.

Other causes of dementia include vascular dementia and frontotemporal dementia.
So what exactly is Lewy body dementia? We use the term LBD fairly generically to refer to two related disorders that both cause dementia.

They have other very similar symptoms and also share the same underlying changes in the brain. But what makes them different is the order in which two of the LBD symptoms appear.

- When a person develops dementia, and around the same time or later also develops symptoms that resemble Parkinson’s disease plus any other LBD symptom, they are diagnosed with “dementia with Lewy bodies.”

- When a person is diagnosed with Parkinson’s disease and has little or no cognitive impairment, but over a year later also develops dementia, they are diagnosed with Parkinson’s disease dementia. This is also a form of LBD.

So determining what name will be used in diagnosing LBD is directly related to whether dementia occurs before or after Parkinson’s symptoms. For simplicity’s sake, in today’s presentation we will refer to both onset types as Lewy body dementia.

LBD is not a new disease. Over 100 years ago Dr. Friedrich Lewy found protein deposits (which are now called Lewy bodies) when he was doing brain autopsies of people with Parkinson’s disease. But it took many years for researchers to understand that these Lewy body deposits are associated not just with Parkinson’s disease, but they also cause a distinct form of dementia.

I will go into LBD’s symptoms more later on, but throughout the talk I will share some real life examples of how the earliest symptoms of LBD can vary, so that you can understand why it is sometimes difficult to diagnose LBD in the early stages. In a recent study, 78 percent of LBD caregivers indicated that LBD was NOT the first diagnosis their loved ones received. The most common initial diagnoses were another form of dementia like Alzheimer’s disease, a movement disorder like Parkinson’s disease or a psychiatric disorder.
Here’s our first example of one person’s early LBD symptoms:

Mildred’s symptoms started subtly and included moving more slowly, shuffling her feet, and having reduced manual dexterity. She also was having problems playing familiar card games or making favorite family recipes. But Mildred was still fairly independent and was able to go to the doctor’s by herself.

After seeing a neurologist, she was diagnosed with Parkinson’s disease. But the cognitive problems remained the bigger concern for the family.

When she progressed to late stage dementia, the family learned she had a form of LBD.
The criteria doctors use to diagnose the two forms of LBD are slightly different, so for today’s discussion we will review the symptoms that lead to a diagnosis of “dementia with Lewy bodies.” Remember, that’s the form of LBD where dementia develops before or at the same time as Parkinson’s-like symptoms.

LBD affects many areas of the brain that control a lot of different functions, which means it causes a lot of symptoms that – to you and me – might seem unrelated. It affects thinking, movement, behavior, sleep and even things like blood pressure and digestion. But LBD symptom combination and severity can vary by person in the early stage of LBD.

Dementia is the one symptom everyone must have in order to get the LBD diagnosis. It causes problems with memory, problem solving, planning, and abstract or analytical thinking. It’s important to point out that, unlike Alzheimer’s disease, noticeable memory problems may not be seen in the early stages.

The other symptoms help to set LBD apart from Alzheimer’s disease, but remember, not every person with LBD will have all these symptoms by the time they are diagnosed:

- **Cognitive fluctuations** involve unpredictable changes in concentration, attention and alertness from day to day or even hour to hour.
- **Visual hallucinations** are seeing things that are not really present.
- **Parkinson’s-like symptoms (or parkinsonism)** include rigidity or stiffness, shuffling gait, tremor and slowness of movement.
- **REM sleep behavior disorder (RBD)** involves acting out dreams, sometimes violently. This symptom appears in some people years and even decades before any changes in cognition. Some sleep partners have reported being physically injured when the disorder was left untreated.
- **Severe sensitivity to antipsychotic medications**, sometimes called neuroleptics, is common in LBD. This is very important because antipsychotic medications are sometimes used to treat hallucinations or other serious behavioral disorders in LBD, but many people have severe reactions to them. Not even the newer, ‘atypical’ antipsychotic medications are considered absolutely safe. They must be used very conservatively, at the lowest dose and for the shortest possible time.
- People with LBD also will have abnormal results on some types of brain scans, showing the loss of a neurotransmitter called dopamine, which affects movement.
The other symptoms listed here are common in LBD but are not part of the diagnostic criteria, such as problems with constipation, incontinence and blood pressure regulation.
People with LBD may experience many types of behavioral symptoms such as:

**Hallucinations**: seeing, hearing or sometimes smelling things that are not there

**Delusions**: are a fixed, false belief; for example, believing that someone is stealing from them, or believing that someone is going to harm them.

**Illusions**: are distorted perceptions; for example; seeing a rope and thinking that it’s a snake.

**Capgras syndrome**: *(SPEAKER: pronounced CAP-grass)* is a recurrent and transient belief that a person, usually someone closely related, has been replaced by an imposter.

**Apathy**: is a loss of interest in activities that used to be enjoyed or a loss of motivation.

**Depression**: is a mood disorder causing sadness, increased frustration, fatigue, loss of interest in activities, and changes in appetite and sleep

**Anxiety**: is a general sense of apprehension or fear and may result in agitation
Bruce was a retired engineer and avid golfer. He started having some mild confusion and nightly, vivid, frightening nightmares that he physically acted out in his sleep. (That’s the REM sleep behavior disorder that I just talked about).

His neurologist diagnosed him in the early 2000’s with the sleep disorder and mild cognitive impairment. At that time, doctors didn’t know that REM sleep behavior disorder is a risk factor for Lewy body dementia.

Two years after his initial diagnosis, Bruce’s confusion had progressed to dementia. He was no longer able to live alone in his own home and he was diagnosed with LBD after seeing a neuropsychologist for cognitive testing.
LBD and Parkinson’s are closely related and may even be part of the same disease spectrum. People with LBD can have many of the same symptoms as people with Parkinson’s disease, for example, problems with movement including slower, smaller movements; impaired dexterity; tremors in limbs that are at rest and/or in use; stiffness; slower, shuffling gait; balance problems and falls.

When someone with Parkinson’s disease later develops dementia, it is called Parkinson’s disease dementia, and is one form of Lewy body dementia.

People with LBD have the same type of biological changes occurring in their brains as people with Parkinson’s. These changes are deposits of the Lewy bodies that I mentioned at the beginning. Lewy bodies are made of naturally-occurring proteins called alpha-synuclein and ubiquitin. (SPEAKER: Synuclein is pronounced “sigh-NEW-klee-in” and ubiquitin is pronounced “you-BICK-quit-in”)

However, these deposits are located in different places in the brain in the early stages of Parkinson’s disease and dementia with Lewy bodies. By the end stages however, the Lewy bodies have progressed to be in the same places in the brain in both disorders.

- When someone has Parkinson’s disease without dementia, the Lewy bodies are found largely in the brainstem only. (This is the lower part of the brain that connects the cerebrum or brain hemispheres with the spinal cord. The brainstem relays motor and sensory signals, and is involved in movement as well as other functions related to mood, sleep, wakefulness, and autonomic function.) These people typically have years of motor symptoms and many of them later also develop dementia.

- But in LBD, the Lewy bodies are not just in the brainstem but also in the cerebral cortex. (This is the outer, deeply folded layer of the brain; often associated with higher thinking.)

There is still a lot that we don’t know about how LBD and Parkinson’s are related. For example, we know that older adults with Parkinson’s disease are at higher risk for developing dementia over time, but we are not sure why it only affects some people with Parkinson’s and not all of them. There is still much more research that needs to be done.
Alzheimer’s and LBD are different not just in what symptoms are involved, but in what proteins are involved.

In Alzheimer’s disease, two proteins called beta amyloid and tau cause the formation of plaques and tangles to form in the brain. *(SPEAKER: beta amyloid is pronounced BAY-tah AM-ah-loyd . Tau rhymes with plow.)*

And, the symptoms of Alzheimer’s are different. In early Alzheimer’s disease, memory loss is prominent, while in LBD, memory is fairly intact, while attention and alertness are reduced and may *mimic* memory problems.

Interestingly, it is common for a person with Alzheimer’s or LBD to have biological changes in the brain of both LBD and Alzheimer’s, though one disorder is normally the more dominant. So you can imagine that if a person has LBD but also displays some mild signs of Alzheimer’s disease, it will make diagnosis all the more challenging for the physician.
So, are you thinking “Boy, this must be a rare disease, because I’ve never heard about it before!” Well, it’s not. There are an estimated 1.3 million people in the United States with LBD – that’s more people than with Parkinson’s disease or even with HIV.

So why haven’t more people heard about it? Well, that’s a good question. LBD wasn’t very well understood by the medical community until the late 20th century. A lot of LBD research is new and not every physician will be up-to-date on research advances.

And the truth is LBD is very hard to diagnose. There is no test or scan that a doctor can do and say with certainty, “You have LBD.”
The criteria for diagnosing LBD are fairly complex and most primary care physicians won’t have much experience diagnosing this disease.

LBDA strongly suggests requesting a referral to a specialist, such as a neurologist, to obtain a diagnosis if LBD is suspected. If you live near a teaching hospital, you may have access to specialty clinics for movement disorders or dementia. These clinics may offer the highest level of LBD clinical expertise in your community and may even provide an opportunity to participate in research studies.

However, outside of a specialty clinic and a few hospital departments like neurology or psychiatry, the rest of the staff in a hospital setting may not be familiar with LBD at all. So it’s often up to the family to educate medical professionals about LBD.
Is there someone in your life (perhaps a parent, sibling, friend, or neighbor) who is having the kinds of symptoms we have been talking about? It can be very uncomfortable to approach the topic of memory problems or cognitive decline with someone you love. But there are good reasons why you should.

An early diagnosis provides the person with dementia an opportunity to share their wishes about decisions that will need to be made in their future.

It also allows for early treatment that can maximize their independence and quality of life, and allows you to talk about safety issues, such as driving and living accommodations.

Equally as important, if a person with LBD is misdiagnosed with another condition, they can end up being treated with certain medications that may worsen their LBD symptoms or even cause serious harm.

So have those difficult discussions and talk with your doctor, if you or someone you love are experiencing any LBD symptoms.
Diagnosing the cause of dementia is difficult and involves many steps.

- The doctor will ask about the person’s medical history and any cognitive, psychological and behavioral symptoms.
- They will do a thorough physical and neurological exam.
- They may order blood tests to rule out other causes for dementia symptoms.
- They will perform tests that assess cognition in general and its specific areas such as memory, language, executive function and visuospatial skills. Some of these are short tests done on the spot; others require a longer appointment with a neuropsychologist. It is important to note that some brief cognitive tests done in the doctor’s office at a preliminary visit, like the Mini-Mental State Exam (MMSE), are not sensitive enough to detect early LBD.
- The doctor may also order one or more brain scans, like an MRI, to rule out other disorders.

Additional tests are recommended to diagnose LBD:

- Neuropsychological exams are much more extensive and sensitive than routine office tests of mental status and can help differentiate among LBD, Alzheimer’s disease, the usually mild changes associated with normal aging, and other neurological conditions.
- Other brain scans can assess changes in brain function and structure, which are helpful in diagnosing LBD.
I have talked a lot about diagnosis, because it is a really big deal. Some people, some families, spend years going from doctor to doctor trying to get a diagnosis.

When the doctor finally does say, “It’s Lewy body dementia,” your next question may be “Can it be treated?”

People with LBD experience symptoms that limit their ability to function normally and may be disturbing. But many of these symptoms can, and should, be treated, because it significantly improves the quality of life for the person with LBD and their primary caregiver.

Medications originally developed to treat Alzheimer’s and Parkinson’s disease, and sleep, psychiatric, and mood disorders are commonly used in LBD.
These medications are commonly prescribed in LBD, in order to:

- lessen cognitive symptoms
- reduce parkinsonism
- treat sleep disorders
- improve cognitive fluctuation or apathy
- decrease hallucinations or delusions and
- treat co-existing depression and anxiety

Medication should be prescribed very carefully, because some medication side effects can make other LBD symptoms worse. For example, levodopa is used to treat the motor symptoms of LBD, but can worsen other features such as sleepiness, cognition, and hallucinations or delusions. Sometimes this is a difficult balancing act even for physicians who are LBD experts.

Bottom line, remember that severe medication sensitivities to antipsychotic medications are common in LBD and that the older, “traditional” antipsychotic drugs should especially be avoided.

Regarding the last item, antidepressants, I’d like to point out that there are numerous medications in these classes of drugs that can be used in LBD, so the two listed here as simply examples.
Not all treatments require medication.

**Physical therapy** includes cardiovascular, strengthening, and flexibility exercises; gait training; fall prevention and home safety evaluations; and general physical fitness programs.

**Occupational therapy** helps maintain skills and promotes functional ability and independence. Music and aromatherapy may reduce anxiety and improve mood.

**Speech therapy** may improve low voice volume, poor enunciation, muscular strength, and swallowing difficulties.

**Individual and family psychotherapy** may be useful for learning strategies to manage emotional and behavioral symptoms and to help make plans that address individual and family concerns about the future.

Sadly, despite all of these treatment options, there is no way to prevent LBD, halt its progression, or cure it.
Knowing what to expect in the future is an essential component of managing LBD, and the long term prognosis is a difficult fact that LBD families need to know.

Like in Alzheimer’s disease, people with Lewy body dementia can have a shorter or longer progression which makes predicting a prognosis difficult. In most cases, the average life expectancy from the time of diagnosis is 5-7 years, though that can vary considerably.

- Generally, those with fewer other health issues will live longer than those with more health issues.
- Better family and social support helps people with LBD live longer than those without much support.
- Appropriate care can improve quality of life for both the patient and caregiver.

As you can imagine, with a disease that affects so many aspects of a person’s abilities from early in the disorder, the level of caregiver burden is quite high.

- Research has shown that people with Lewy body dementia are more functionally impaired than people with Alzheimer’s disease.
- And people with Lewy body dementia are more impaired in self-care skills, motor skills and experience more neuropsychiatric symptoms, especially hallucinations, than people with Alzheimer’s.
Here’s another example of how LBD symptoms can present:

Betty was first diagnosed with Parkinson’s disease. She didn’t have much of a tremor, but her handwriting had become small, she had a shuffling gait and became rather stooped over.

But when she started having hallucinations, her daughter became alarmed. Betty was also having problems with confusion and visual-spatial orientation, like the day she walked to the edge of a tile floor but was unable to step onto the adjoining carpet.

Soon, Betty’s Parkinson’s progressed to Parkinson’s disease dementia, which is one form of Lewy body dementia.
The Lewy Body Dementia Association is the only organization in the country solely dedicated to issues facing LBD families. They are leading the call for all changes that will result in a better life for those affected by Lewy body dementias.

Their mission is to:

- Educate and support LBD families,
- Increase awareness about LBD in the public and healthcare profession, and
- Increase research.

Help is available at LBDA!
We can’t make LBD a household name without your help.

We’d like everyone here to find some way, no matter how small, to pass along what you’ve learned today.

Tell someone else about LBD. Pass along one of today’s handouts or post something about LBD on Facebook.

If you have been personally touched by LBD or have professional skills you would like to share, consider volunteering with LBDA.

And we hope you will make a donation to LBDA. Every dollar you donate is like a candle that shines just a little bit more light to raise awareness of LBD.
I’d like to thank you for coming out today to learn more about LBD. You’ve been a very attentive audience and it’s been a pleasure being here.

Thank you!