

## GET THE FACTS ABOUT LEWY

Introduce those you care about to the facts about Lewy body dementia.

**FACT:** Lewy body dementia (LBD) is the most misdiagnosed form of dementia.

**FACT:** LBD is the second most common cause of progressive dementia behind Alzheimer's disease.

**FACT:** LBD affects approximately 1.4 million Americans, most often after the age of 50.

**FACT:** LBD is NOT usually hereditary.

### WHAT IS LEWY BODY DEMENTIA?

Lewy body dementia (LBD) is a progressive brain disorder in which Lewy bodies (abnormal deposits of a protein called alpha-synuclein) build up in areas of the brain that regulate behavior, cognition, and movement.

A complex disease, LBD can present with a range of symptoms including problems with thinking, memory, moving, sleep and/or changes in behavior. Progressively debilitating, LBD can cause people to experience visual hallucinations or act out their dreams.

### WHAT IS THE DIFFERENCE BETWEEN LBD AND DEMENTIA WITH LEWY BODIES?

LBD is an umbrella term for two closely related clinical diagnoses: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD).

### WHAT CAUSES LBD?

The causes of LBD are not yet well understood, but research is ongoing in this area. There appear to be multiple factors involved, including genetic and environmental risk factors that combine with natural aging processes to make someone susceptible to LBD.

### WHAT ARE THE SIGNS AND SYMPTOMS OF LBD?

This condition impairs thinking, such as memory, executive function (planning, processing information), or the ability to understand visual information. People with LBD may have fluctuations in attention or alertness; problems with movement including slowness, stiffness, difficulty walking, and tremors; hallucinations; and alterations in sleep and behavior. People with LBD may also have altered autonomic function, such as blood pressure control or bowel and bladder function.

### ABOUT THE LEWY BODY DEMENTIA ASSOCIATION

The Lewy Body Dementia Association is a 501(c)(3) national nonprofit health organization dedicated to raising awareness of Lewy body dementia, supporting people with LBD, their families and caregivers, and promoting scientific advances. Through outreach, education and research, LBDA supports all those affected by Lewy body dementia.

### WE'RE HERE TO HELP

Visit the LBDA website at [lbda.org](http://lbda.org) to learn more about LBD, find resources to get the help you need, and connect with the LBD community.

### LEWY LINE

You are not alone. Experienced LBD volunteers are available to answer questions and provide support. Call toll-free 800.539.9767 or email [support@lbda.org](mailto:support@lbda.org).

### LOCAL LBD SUPPORT GROUPS

Support groups provide the opportunity to connect with others who are seeking support, resources and information in a group setting. Find a local LBD support group near you or join one online by visiting [lbda.org](http://lbda.org).

### FACEBOOK SUPPORT GROUPS

We know it can be difficult to attend support groups in person. That's why we created the LBDA Facebook support groups, where you can meet and share your experiences and insights with caregivers and those living with an LBD diagnosis.

### LBD SOCIAL NETWORKING

Connect with the LBDA and other LBD families to get support and help us raise awareness of LBD. Visit [lbda.org](http://lbda.org) to connect with us on Facebook, Twitter and LinkedIn.

**For more information on LBD and support groups, please visit the Lewy Body Dementia Association website at [www.lbda.org](http://www.lbda.org).**

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# IS IT LEWY?

**Recognizing when it's not  
Alzheimer's or Parkinson's disease**



## EARLY DIFFERENTIATING SYMPTOMS

	LBD	Alzheimer's	Parkinson's
Decline in thinking abilities that interferes with everyday life	Always	Always	Possible years after diagnosis
Significant memory loss	Possible	Always	Possible years after diagnosis
Planning or problem-solving abilities	Likely	Possible	Possible
Difficulty with sense of direction or spatial relationships between objects	Likely	Possible	Possible
Language problems	Possible	Possible	Possible
Fluctuating cognitive abilities, attention or alertness	Likely	Possible	Possible
Changes in mood	Possible	Possible	Possible
Visual hallucinations	Likely	Unlikely	Possible
Slowed movements, small, shuffling steps, problems using hands, tremors	Likely	Unlikely	Always
Balance problems and/or falls	Possible	Unlikely	Likely
Acting out dreams	Possible	Unlikely	Possible

## HOW IS LBD DIAGNOSED AND WHAT TYPE OF DOCTOR DO I NEED TO VISIT?

Doctors diagnose LBD based on the patient's history, examination, and potentially other blood tests or brain scans to exclude other causes of dementia, movement disorders, or behavioral problems. There are no medical tests that can diagnose LBD with absolute certainty during life, so when a doctor suspects a person has LBD based on their clinical features, they are diagnosed with "probable LBD." The only way to be certain of the diagnosis is with an autopsy.

Primary care practitioners should be told about any cognitive, emotional, movement, or other physical changes. If LBD is suspected, a neurologist is recommended for diagnostic evaluation and management. Neurologists have the specialized knowledge necessary to diagnose specific types of dementia or movement disorders, as do psychiatrists and geriatric psychiatrists.

Some neurologists have advanced or specialty training in the care of people with dementia and/or parkinsonian movement disorders. Neuropsychologists also play an important role in helping to diagnose LBD and testing memory and cognitive functions. Geriatricians, who specialize in treating older adults, are also usually familiar with the different forms of dementia.

A diagnosis by specialists very familiar with LBD may be accurate up to 90% of the time.

### IS THERE A CURE FOR LBD?

Currently, there is no cure for this disease. Practitioners prescribe medications to reduce symptoms. Research is continuing so that better medications can be developed and a cure can be found.



## WHAT RESOURCES ARE AVAILABLE TO HELP PRACTITIONERS IN THE HEALTHCARE COMMUNITY RECOGNIZE, DIAGNOSE, AND TREAT PEOPLE WITH LBD?

The Lewy Body Dementia Association (LBDA) has developed a Diagnostic Symptoms Checklist to help people, caregivers, and healthcare providers quickly and easily identify symptoms that are required for the diagnosis of LBD.

This free checklist can be downloaded and printed for unlimited use by both medical practitioners and individuals who want to discuss LBD with their doctor: [lbda.org/lbd-diagnostic-symptoms-checklist](http://lbda.org/lbd-diagnostic-symptoms-checklist).

## WHAT SUPPORT IS AVAILABLE FOR PEOPLE WITH LBD AND THOSE WHO MAY HAVE IT?

If you suspect that you or someone you love is having symptoms of LBD, call your doctor right away. Don't forget to fill out the patient's section of LBDA's diagnostic symptoms checklist and take it with you to your doctor's appointment. An early diagnosis provides the person with LBD an opportunity to share their wishes about decisions that will need to be made in their future. It also allows practitioners to give proper treatment that can extend independence and improve quality of life. Living well with LBD is possible with help and guidance.



## CONSIDER THE LBDA RESEARCH CENTERS OF EXCELLENCE (RCOE)

One of the top national research priorities for Lewy body dementia is to find new treatments for symptoms that have the greatest impact on those with LBD and their caregivers. The LBDA RCOE program was established to address a common problem most LBD families face - finding a physician with experience in LBD clinical management. By directing families to these centers, this program will also provide a nationwide network of places for LBD education, care and support. The RCOE network features 25 of medicine's most prestigious academic LBD research centers in the country. These centers can be found at [lbda.org](http://lbda.org).