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## Diseases and Conditions

# Lewy body dementia

By Mayo Clinic Staff

Lewy body dementia, the second most common type of progressive dementia after Alzheimer's disease, causes a progressive decline in mental abilities.

It may also cause visual hallucinations, which generally take the form of objects, people or animals that aren't there. This can lead to unusual behavior such as having conversations with deceased loved ones.

Another indicator of Lewy body dementia may be significant fluctuations in alertness and attention, which may include daytime drowsiness or periods of staring into space. And, like Parkinson's disease, Lewy body dementia can result in rigid muscles, slowed movement and tremors.

In Lewy body dementia, protein deposits, called Lewy bodies, develop in nerve cells in regions of your brain involved in thinking, memory and movement (motor control).

Lewy body dementia signs and symptoms may include:

- **Visual hallucinations.** You may see visual hallucinations, such as colors, shapes, animals or people that aren't there. Hallucinations may be one of the first symptoms of Lewy body dementia. Some people also may experience sound (auditory), smell (olfactory) or touch (tactile) hallucinations.
- **Movement disorders.** You may experience symptoms similar to those of Parkinson's disease (parkinsonian symptoms), such as slowed movement, rigid muscles, tremors or a shuffling walk.
- **Poor regulations of body function.** Blood pressure, pulse, sweating and digestive process are regulated by a part of the nervous system that is often affected by Lewy body dementia. This can result in dizziness, falls and bowel issues.
- **Cognitive problems.** You may experience thinking (cognitive) problems similar to

problems experienced in Alzheimer's disease, such as confusion, reduced attention span and eventually memory loss.

- **Sleep difficulties.** You may have a sleep disorder called rapid eye movement (REM) sleep behavior disorder that can cause you to physically act out your dreams while you're asleep.
- **Fluctuating attention.** You may have frequent episodes of drowsiness, long periods of staring into space, long naps during the day or disorganized speech.
- **Depression.** You may experience depression sometime during the course of your illness.

The cause of Lewy body dementia isn't known, but the disorder may be related to Alzheimer's or Parkinson's disease.

- Lewy bodies contain a protein associated with Parkinson's disease.
- Lewy bodies often are present in the brains of people with Parkinson's disease, Alzheimer's disease and other dementias.
- People who have Lewy bodies in their brains also have the plaques and tangles associated with Alzheimer's disease.

Although the cause of Lewy body dementia isn't clear, several factors appear to increase the risk of developing the disease. They include:

- Being older than 60
- Being male
- Having a family member with Lewy body dementia

Lewy body dementia is progressive. Signs and symptoms worsen, causing:

- Severe dementia
- Death, on average about eight years after onset of the condition

You'll probably first bring your symptoms to the attention of your family doctor, who may refer you to a doctor trained in dementia — usually a doctor trained in brain and nervous system conditions (neurologist) or mental health conditions (psychiatrist).

Because appointments can be brief, and because there's often a lot to talk about, it's a good idea to be well prepared for your appointment. Here's some information to help you get ready for your appointment, and what to expect from your doctor.

## What you can do

Plan ahead and write lists of important information, including:

- **Write a detailed description** of all your symptoms.

- **Make a list of all medications**, vitamins or supplements that you're taking.
- **Write down questions** to ask your doctor, such as what tests or treatments he or she may recommend.
- **Take a family member or friend along.** A family member or close friend may tell your doctor about symptoms you may not have noticed.

## What to expect from your doctor

Your doctor is likely to ask you and your spouse, partner, or close friend a number of questions about:

- Changes in your memory, personality and behavior
- Visual hallucinations
- Medications you're taking
- Your history of stroke, depression, alcohol abuse, head trauma or other neurological disorders

To be diagnosed with Lewy body dementia, you must have experienced a progressive decline in your ability to think, as well as two of the following:

- Fluctuating alertness and thinking (cognitive) function
- Repeated visual hallucinations
- Parkinsonian symptoms

In addition, one or more of the following features are considered supportive of the diagnosis of Lewy body dementia:

- REM sleep behavior disorder, a condition in which people act out their dreams during sleep
- Autonomic dysfunction, which involves instability in blood pressure and heart rate, poor regulation of body temperature, sweating, and related symptoms

No single test can diagnose Lewy body dementia. Instead, doctors diagnose your condition through ruling out other conditions that may cause similar signs and symptoms. Tests may include:

## Neurological and physical examination

As part of your physical examination, your doctor may also check for signs of Parkinson's disease, strokes, tumors or other medical conditions that can impair brain function as well as physical function. The neurological examination may test:

- Reflexes

- Eye movements
- Balance
- Sense of touch

## Assessment of mental abilities

A short form of this type of test, which assesses your memory and thinking skills, can be done in less than 10 minutes in your doctor's office but is generally not useful in distinguishing Lewy body dementia from Alzheimer's disease. Longer forms of neuropsychological testing can take several hours, but these tests help identify your condition.

Your results are then compared with those of people from a similar age and education level. This can help distinguish normal from abnormal cognitive aging, and may help identify patterns in cognitive functions that provide clues to the underlying condition.

## Blood tests

Simple blood tests can rule out physical problems that can affect brain function, such as vitamin B-12 deficiency or an underactive thyroid gland.

## Electroencephalogram (EEG)

If your confusion comes and goes, your doctor may suggest an EEG. This test can help determine if your symptoms may be caused by seizures or Creutzfeldt-Jakob disease, a rare, degenerative brain disorder that leads to dementia. This painless test records the electrical activity in your brain via wires attached to your scalp.

## Brain scans

Your doctor may order an MRI, PET or CT scan to check for evidence of Alzheimer's disease, stroke or bleeding, and to rule out the possibility of a tumor.

Your doctor may order a sleep evaluation to assess for REM sleep behavior disorder or an autonomic function test to look for signs of heart rate and blood pressure instability.

Treatment can be challenging, and there's no cure for Lewy body dementia. Instead, doctors treat the individual symptoms.

## Medications

- **Cholinesterase inhibitors.** These Alzheimer's disease medications, such as rivastigmine (Exelon), work by increasing the levels of chemical messengers believed to be important for memory, thought and judgment (neurotransmitters) in the brain.

This can help improve alertness and cognition, and may help reduce hallucinations and other behavioral problems. Possible side effects may include gastrointestinal upset, excessive salivation and tearing, and frequent urination.

- **Parkinson's disease medications.** These medications — such as carbidopa-levodopa (Sinemet) can help reduce parkinsonian symptoms, such as rigid muscles and slow movement — in some people with Lewy body dementia. However, these medications may also cause increased confusion, hallucinations and delusions.
- **Antipsychotic medications.** These medications, such as quetiapine (Seroquel), olanzapine (Zyprexa) and others, may somewhat improve delusions and hallucinations. However, some people with Lewy body dementia have a dangerous sensitivity to some of these drugs. Reactions, which are sometimes irreversible, can include severe parkinsonian symptoms and confusion.
- **Medications to treat symptoms.** Your doctor may prescribe medications to treat other symptoms associated with Lewy body dementia, such as sleep or movement problems.

## Therapies

Because antipsychotic drugs can worsen Lewy body dementia symptoms, it might be helpful to initially try nondrug approaches, such as:

- **Merely tolerating the behavior.** Many times a person with Lewy body dementia isn't distressed by the hallucinations and even recognizes them as such. In these cases the side effects of medication may be worse than the experience of the hallucinations themselves.
- **Modifying the environment.** Reducing clutter and distracting noise can make it easier for someone with dementia to focus and function. It can also reduce the risk that the person with Lewy body dementia will misperceive objects in the environment and produce behavior similar to hallucinations.
- **Modifying your responses.** A caregiver's response to a behavior can make the behavior worse. It's best to avoid correcting and quizzing a person with dementia. Reassuring the person and validating his or her concerns can help resolve many situations.
- **Modifying tasks and daily routines.** Break tasks into easier steps and focus on successes, not failures. Structure and routine during the day also help reduce confusion in people with dementia.

Each person with Lewy body dementia and other dementias experience symptoms and progression differently. Consequently, techniques to care for each person vary. Caregivers may need to adapt the following tips to individual situations:

- **Enhance communication.** When talking with the person with Lewy body dementia, maintain eye contact. Speak slowly, in simple sentences, and don't rush the response.

Present only one idea or instruction at a time. Use gestures and cues, such as pointing to objects.

- **Encourage exercise.** Exercise benefits everyone, including people with dementia. Benefits of exercise include improved physical function, more controlled behavior and fewer depression symptoms. Some research shows physical activity may slow the progression of impaired thinking (cognitive) function in people with dementia.
- **Encourage participation in games and thinking activities.** Participating in games, crossword puzzles and other activities that involve using thinking skills may help slow mental decline in people with dementia.
- **Establish a nighttime ritual.** Behavior issues may be worse at night. Try to establish going-to-bed rituals that are calming and away from the noise of television, meal cleanup and active family members. Leave night lights on to prevent disorientation.

Limiting caffeine during the day, discouraging daytime napping and offering opportunities for exercise during the day may help prevent nighttime restlessness.

People with dementia often experience a worsening of their symptoms when they are frustrated or anxious. The following techniques may help promote relaxation.

- Music therapy, which involves listening to soothing music
- Pet therapy, which involves the use of animals, such as visits from dogs, to promote improved moods and behaviors in people with dementia
- Aromatherapy, which uses fragrant plant oils
- Massage therapy

People with Lewy body dementia often experience a mixture of emotions, such as confusion, frustration, anger, fear, uncertainty, grief and depression.

You can help a person cope with the disease by listening, reassuring the person that he or she still can enjoy life, being supportive and positive, and doing your best to help the person retain dignity and self-respect.

If you're a caregiver for someone with Lewy body dementia, watch the person closely to make sure he or she doesn't fall, lose consciousness or react negatively to medications. You can should also reassure the person during times of confusion, delusions or hallucinations.

## Looking after yourself

The physical and emotional demands of caregiving can be exhausting. You may experience feelings of anger, guilt, frustration, discouragement, worry, grief or social isolation. If you're a caregiver for someone with Lewy body dementia, you can help yourself and help prevent caregiver burnout by doing the following:

- Ask friends or other family members for help when you need it. Consider in-home health services to assist with the care of the person with Lewy body dementia.
- Take care of your health. Exercise regularly and eat a healthy diet.
- Learn as much about the disease as you can. Ask questions of doctors, social workers and others involved in the care of the person with Lewy body dementia.
- Join a support group.

Many people with Lewy body dementia and their families can benefit from counseling or local support groups. Contact your local agencies on health or aging to get connected with support groups, doctors, resources, referrals, home care agencies, supervised living facilities, a telephone help line and educational seminars.

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