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# Advice for People Living with Lewy Body Dementia

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Coping with a [diagnosis of Lewy body dementia](#) (LBD) and all that follows can be challenging. Getting support from family, friends, and professionals is critical to ensuring the best possible quality of life. Creating a safe environment and preparing for the future are important, too. Take time to focus on your strengths, enjoy each day, and make the most of your time with family and friends. Here are some ways to live with LBD day to day.

## Getting Help

Your family and close friends are likely aware of changes in your thinking, movement, or behavior. You may want to tell others about your diagnosis so they can better understand the reason for these changes and learn more about LBD. For example, you could say that you have been diagnosed with a brain disorder called [Lewy body dementia](#), which can affect thinking,



movement, and behavior. You can say that you will need more help over time. By sharing your diagnosis with those closest to you, you can build a support team to help you manage LBD.

As LBD progresses, you will likely have more trouble managing everyday tasks such as taking medication, paying bills, and driving. You will gradually need more assistance from family members, friends, and perhaps professional [caregivers](#). Although you may be reluctant to get help, try to let others partner with you so you can manage responsibilities together. Remember, LBD affects your loved ones, too. You can help reduce their stress when you accept their assistance.

Finding someone you can talk with about your diagnosis—a trusted friend or family member, a mental health professional, or a spiritual advisor—may be helpful.

# Consider Safety

The changes in thinking and movement that occur with LBD require attention to safety issues. Consider these steps:

- Fill out and carry the [LBD Medical Alert Wallet Card](#) and present it any time you are hospitalized, require emergency medical care, or meet with your doctors. It contains important information about medication sensitivities.
- Consider subscribing to a medical alert service, in which you push a button on a bracelet or necklace to access 911 if you need emergency help.
- Address safety issues in your home, including areas of fall risk, poor lighting, stairs, or cluttered walkways. Think about home modifications that may be needed, such as installing grab bars in the bathroom or modifying stairs with ramps. Ask your doctor to refer you to a home health agency for a home safety evaluation.
- Talk with your doctor about LBD and [driving](#), and have your driving skills evaluated, if needed.

# Plan for Your Future

There are many [ways to plan ahead](#). Here are some things to consider:

- If you are working, consult with a legal and financial expert about planning for disability leave or retirement. Symptoms of LBD will interfere with work performance over time, and it is essential to plan now to obtain benefits you are entitled to.
- Consult with an attorney who specializes in elder law or estate planning to help you write or update [important documents](#), such as a living will, healthcare power of attorney, and will.
- [Identify local resources](#) for home care, meals, and other services *before* you need them so you know whom to call when the time comes.
- Explore moving to a retirement or continuing care community where activities and varying levels of care can be provided over time, as needed. Ask about staff members' experience caring for people with LBD.

# Find Enjoyment Every Day

It is important to focus on living with LBD. Your attitude can help you find enjoyment in daily life. Despite the many challenges and adjustments, you can have moments of humor, tenderness, and gratitude with the people closest to you.

Make a list of events and activities you can still enjoy—then find a way to do them! For example, listening to music, exercising, or going out for a meal allows you to enjoy time with family and friends. If you can't find pleasure in daily life, consult your doctor or another healthcare professional to discuss effective ways to cope and move forward. Let your family know if you are struggling emotionally so they can offer support.

# For More Information About Living with LBD

## NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

1-800-438-4380 (toll-free)

[adear@nia.nih.gov](mailto:adear@nia.nih.gov)

[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

The National Institute on Aging's ADEAR Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

## Lewy Body Dementia Association

1-404-935-6444

1-800-539-9767 (toll-free LBD Caregiver Link)

[www.lbda.org](http://www.lbda.org)

## Eldercare Locator

1-800-677-1116 (toll-free)

[www.eldercare.gov](http://www.eldercare.gov)