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How to Care for a Person with Lewy Body Dementia

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As someone who is caring for a person with LBD, you will take on many different responsibilities over time. You do not have to face these responsibilities alone. Many sources of help are available, from adult day centers and [respite care](#) to online and in-person support groups.

Below are some important actions you can take to adjust to your new roles, be realistic about your situation, and [care for yourself](#).

Educate Others About LBD

Most people, including many healthcare professionals, are not familiar with LBD. In particular, emergency room physicians and other hospital workers may not know that



people with LBD are extremely [sensitive to antipsychotic medications](#). Caregivers can educate healthcare professionals and others by:

- Informing hospital staff of the LBD diagnosis and medication sensitivities, and requesting that the person's neurologist be consulted before giving any drugs to control behavior problems.
- Sharing educational pamphlets and other materials with doctors, nurses, and other healthcare professionals who care for the person with LBD. Materials are available from the [Lewy Body Dementia Association](#)
- Teaching family and friends about LBD so they can better understand your situation.

Prepare for Emergencies

People with LBD may experience sudden declines in functioning or unpredictable behaviors that can result in visits to the emergency room. Infections, [pain](#), or other medical conditions often cause increased confusion or behavioral problems. Caregivers can prepare for emergencies by having available:

- A [list of the person's medications](#) and dosages
- A list of the person's health conditions, including allergies to [medicines](#) or foods
- Copies of health insurance card(s)
- Copies of [healthcare advance directives](#), such as a living will
- Contact information for doctors, family members, and friends

Adjust Expectations

You will likely experience a wide range of emotions as you care for the person with LBD. Sometimes, caregiving will feel loving and rewarding. Other times, it will lead to anger, impatience, resentment, or [fatigue](#). You must recognize your strengths and limitations, especially in light of your past relationship with the person. Roles may change between a husband and wife or between a parent and adult children. Adjusting expectations can allow you to approach your new roles realistically and to seek help as needed.

People approach challenges at varied paces. Some people want to learn everything possible and be prepared for every scenario, while others manage best by taking one day at a time. Caring for someone with LBD requires a balance. On one hand, you should [plan for the future](#). On the other hand, you may want to make each day count in personal ways and focus on creating [enjoyable and meaningful moments](#).

A Peaceful Routine

Susan realized that her mother, Estelle, could not manage a lot of stimulation. Estelle easily became agitated and confused, so Susan avoided taking her to places with large crowds or noisy environments. Susan discovered that soothing music calmed Estelle and used it to help her relax when she grew anxious and irritable. Establishing a routine with familiar faces in smaller groups has allowed Estelle to enjoy a better quality of life, despite the challenges caused by dementia with Lewy bodies.

Care for Yourself

As a caregiver, you play an essential role in the life of the person with LBD, so it is critical for you to maintain your own health and well-being. You may be at increased risk for poor [sleep](#), [depression](#), or illness as a result of your responsibilities. Watch for signs of physical or emotional fatigue such as irritability, withdrawal from friends and family, and changes in appetite or weight.

Address Family Concerns

Not all family members may understand or accept LBD at the same time, and this can create conflict. Some adult children may deny that parents have a problem, while others may be supportive. It can take a while to learn new roles and responsibilities.

Family members who visit occasionally may not see the symptoms that primary caregivers see daily and may underestimate or minimize your responsibilities or stress. Professional counselors can help with family meetings or provide guidance on how families can work together to manage LBD.

Although LBD and Alzheimer’s disease are different disorders, they share similar family concerns. For more information, read [Helping Family and Friends Understand Alzheimer’s Disease](#) and [Helping Kids Understand Alzheimer’s Disease](#).

For More Information About Caring for a Person with LBD

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

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

adear@nia.nih.gov

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

Eldercare Locator

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

www.eldercare.gov

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