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Caring for a Person With Lewy Body Dementia

As someone caring for a person with [Lewy body dementia \(LBD\)](#), 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.

What Is Lewy Body Dementia?



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

Educate others about Lewy body dementia

Most people, including many health care 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 health care 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 materials with health care professionals who care for the person with LBD. Materials are available from [NIH](#), as well as the [Lewy Body Dementia Association](#) and the [Lewy Body Dementia Resource Center](#).
- 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 preparing for the following:

- A [list of the person's medications](#) and dosages
- A list of the person's health conditions, including allergies to [medicines](#) or foods. [This medical alert card can help](#).
- Copies of health insurance card(s)
- Copies of [health care 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](#). 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 prefer to take one day at a time. Caring for someone with LBD requires a balance. [Plan for the future](#), but also focus on creating [enjoyable and meaningful moments](#).

A peaceful routine

Susan realized that her mother, Estelle, did not thrive around loud noises or in busy rooms. Estelle easily became agitated and confused, so Susan avoided taking her to places with large crowds or noisy environments. Susan found that soothing music calmed Estelle when she grew anxious. Establishing a routine with familiar faces in smaller groups has allowed Estelle to enjoy a better quality of life, despite having Lewy body dementia.

Understand behavioral changes in Lewy body dementia

Behavioral and mood problems in people with LBD can arise from hallucinations, delusions, [pain](#), illness, stress, or anxiety. They may also be the result of frustration, fear, or feeling overwhelmed. The person may resist care or lash

out verbally or physically.

[Hallucinations and delusions](#) are among the biggest challenges for LBD caregivers. The person with LBD may not understand or accept that the hallucinations are not real and may become agitated or anxious. Instead of arguing, caregivers can help by responding to the fears expressed. By tuning in to the person's emotions, caregivers can offer empathy and concern, maintain the person's dignity, and limit further tension.

Caregivers can try a variety of strategies to handle such challenging behaviors. Some behavioral problems can be managed by making changes in the person's environment and/or treating medical conditions. Other problems may require medication.

It's also common for people with LBD to have difficulty falling asleep. Certain sleep problems can be addressed without medications. Increasing daytime exercise or activities and avoiding lengthy or frequent naps can promote better sleep. Avoiding alcohol, caffeine, or chocolate late in the day can help, too. Some over-the-counter medications can also affect sleep, so [review all medications and supplements](#) with a physician.

Caregivers can alter the home environment to try to minimize anxiety and stress for the person with LBD. In general, people with LBD benefit from having simple tasks, consistent schedules, regular exercise, and adequate sleep. Large crowds or overly stimulating environments can increase confusion and anxiety.

Find time to care for yourself

As a caregiver, it is critical for you to take care of 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.

All caregivers need time away from caregiving responsibilities to [maintain their well-being](#). Learn to accept help when it's offered, and learn to ask family and friends for support. One option is professional [respite care](#), which can be obtained through home care agencies and adult day programs. Similarly, friends or family can come to the home or take the person with LBD on an outing to give you a break.

Discuss Lewy body dementia diagnosis with family

Not all family members may understand or accept LBD at the same time. This can create conflict. Some adult children may deny that their parent has 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 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 Children Understand Alzheimer's Disease](#).

Make plans for the end of life

[Advance care planning](#) is an important part of end of life care. Planning ahead can improve the quality of life of the person with LBD and their caregivers and help ensure that the person with LBD has input into [health care](#) and [legal and financial decisions](#). Having these conversations early allows the person to actively participate in the decision-making process and express their personal wishes.

For health care providers and caregivers who don't have experience with LBD, it can be challenging to recognize the end of life. LBD is unpredictable. It can be hard to know when the person will die, and the process may be shorter or longer than expected, which may make coping more difficult. Staying in touch with the person's physician can help you decide when to pursue [end of life care](#) and what



to expect towards the end of life. Some physicians may be unlikely to initiate end of life conversations. It is important for caregivers to take an active role during appointments and [come prepared](#).

Spending time and doing simple activities together towards the end of life may help ease the process. Listening to music, spending time outdoors, or watching a favorite television show are just a few examples of activities you can do. Some family members find a lot of value in simply holding their loved one's hand and talking to them in their last few days.

Many caregivers feel relief when death happens, for themselves and the person with LBD. It is important to realize that these feelings are normal. [Get help for your grief](#).

Learn more about [end of life care](#).

For more information about caring for a person with Lewy body dementia

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

800-438-4380

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's 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.

Alzheimers.gov

www.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

Eldercare Locator

800-677-1116

eldercarelocator@USAgings.org

<https://eldercare.acl.gov>

Lewy Body Dementia Association

404-935-6444

800-539-9767 (LBD Caregiver Link)

www.lbda.org

Lewy Body Dementia Resource Center

833-LBDLINE

norma@lbdny.org

<https://lewybodyresourcecenter.org>

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

Content reviewed: June 28, 2018

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