

CAREGIVING BRIEF: COMMUNITY RESOURCES

“I’ve never cared for anyone with dementia before. How do I know where to start?”

“Mom is exhausted and we need to take some of the burden off her shoulders before she gets sick herself. Where can we find help with caring for Dad?”

Because Lewy body dementia (LBD) is complex and progressive, people with the disorder and family caregivers may feel overwhelmed with their responsibilities. Learn more about the different types of community resources available. And contact your local resources for more information BEFORE you actually need them.

Clinical care – A physician who specializes in neurology, psychiatry, or geriatrics is a valuable part of the care team in LBD. Physical, speech, and occupational therapists may help maximize functional ability. Psychologists are helpful in addressing the emotional impact of the disease. Palliative care providers help families identify and achieve care goals that maximize quality of life for the person with LBD as the disease progresses.

Care at home – Some resources can help extend the length of time a person with LBD can live safely in one’s homes, and also lighten the work for the family caregiver. Many communities have a service that will deliver meals once a day, such as Meals on Wheels. Senior transportation services provide door-to-door transportation by van or car at a reduced cost. Home care agencies can provide companion services, housekeeping, and personal care such as bathing. Home health agencies provide medical care at home that requires a nurse or physical therapist.

Adult day services provide a safe and supervised environment where a person with LBD can have increased social interaction and participate in enjoyable activities. This can provide respite (which simply means a much needed break) to the caregiver, and may enable the caregiver to continue working outside the home.

Residential care – There is a wide range of living options that can be helpful to LBD families throughout the course of the disease. Long term care communities are run by nonprofit and for profit corporations and vary in the type of care provided. Some offer options for adults who can still live independently, others provide care for those who need moderate assistance, and some provide skilled nursing care. There are long term care communities with assisted living units or buildings especially designed for adults with dementia (often called memory care). Residential care can also provide temporary respite care, allowing for caregivers to take some time off to rest or travel. Continuing care retirement communities (CCRC) offer several levels of health care at one location: independent living, assisted living, skilled nursing, rehabilitation, and memory care.

Legal and Financial – Any time a person is diagnosed with a form of dementia, it is recommended they review their legal and financial plans with a professional. Legal aspects of being a caregiver do not need to be complicated or intimidating. An elder law attorney has specialized training in legal matters common to older adults, such as trusts, wills, estates, medical powers of attorney, advance directives, and benefits provided by the government. Legal documents require the person with LBD to provide informed consent, and witnesses must verify that they are competent and of sound mind. LBD affects cognitive ability, so it is best to complete these documents as early in the course of the disease as possible. A financial advisor may be helpful to review current finances and discuss planning for future medical and care expenses.

Other services

Geriatric care managers provide help managing a range of care services and advocate for their client's needs. This service may be especially helpful for long distance caregivers when there is no local caregiver available.

Local support groups are especially helpful to family caregivers, allowing them some time to talk face to face with other caregivers about their daily challenges and the sometimes conflicting or difficult emotions most caregivers experience.

Counselors, therapists, and other mental health professionals can help caregivers cope with psychological issues such as ambiguous loss and anticipatory grief.

Church and civic organizations may have volunteers who can provide a home cooked meal, or visit socially with the person with LBD so the caregiver may run errands or have some social time of their own.

Governmental agencies are often very helpful. Look for your local Area Agency on Aging, which specializes in matters pertaining to older adults and can sometimes refer families to other helpful resources.

LEARN MORE FROM LBDA:

- Find a local LBD caregiver support group: <https://www.lbda.org/lbd-local-support-groups>
- Find other caregiver resources: <https://www.lbda.org/content/more-caregiver-resources>

Other Resources

- Find local resources through the Family Caregiver Alliance's Family Care Navigator: <https://www.caregiver.org/>
- Eldercare Locator is a nationwide directory assistance service helping older people and their caregivers locate local support and resources: <http://www.eldercare.gov/>
- CaringInfo provides information on advance care planning, palliative care, hospice, and grief and loss for anyone who is planning ahead, caregiving, living with a serious illness or grieving a loss: <http://www.caringinfo.org>

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