

Respite Care for ALS

Respite care is any type of short-term caregiving assistance that provides rest and relief for the primary caregiver (often a spouse, family member, or close friend). Depending on your support network and the resources available in your area, you may be able to find respite care at no cost.

How can respite care help ALS caregivers?

No matter how much you love someone, caring for a person living with ALS can be physically demanding and emotionally draining. Many caregivers feel so overwhelmed trying to juggle the demands of caregiving and day-to-day life that they don't eat well, sleep enough, get exercise, see friends, or do anything other than work and provide care. This can lead to feelings of anger and resentment, which can put an emotional strain on your relationship.

Respite care can help minimize exhaustion, depression, irritability, social withdrawal, and other effects of caregiver burnout. When caregivers have time for their own self-care, they are often better caregivers.

Why do some families not use respite care for ALS?

Primary caregivers often feel guilty for leaving their loved one's side, even if it is just for a few hours. But caregivers need to recognize that not only do they deserve breaks, they need them for their own physical, mental, and emotional health. Encouraging your loved one to take some guilt-free personal time is a gift that will benefit both of you.

Where can we find respite care?

Respite care can take many different forms. It may be provided by professional caregivers, healthcare professionals, family, friends, or volunteers.

Respite Care Grants and Programs

Some local ALS organizations have grants that pay caregivers to come to your home for a certain number of hours a month at no cost to you. Ask if there are any programs like this in your area. You can also check the ARCH National Respite website (<https://archrespite.org/caregiver-resources/respitelocator>) for information on state respite coalitions, grants, and services.

Home Care (non-medical)

If your local ALS organization doesn't have funding for respite care, they should have a list of recommended caregivers and agencies who have some experience working with ALS. You will

probably need to pay out of pocket because Medicare and private insurance don't typically cover non-medical home care for assistance with activities of daily living like transferring, eating, bathing, dressing, and toileting.

Family, Friends, and Community

If the cost of professional caregiving is too great, or if you need additional support, you can ask for help from family, friends, or your greater community. It may feel uncomfortable to ask, especially if you're used to being independent, but people often want to help if they know what you need.

Home Health Services

If your neurologist prescribes skilled nursing services or physical, occupational, or speech language therapy, then Medicare, Medicaid, and private insurance should cover these intermittent, short-term home health services. These professionals will come to your home to work with you.

Hospice Care

If you are enrolled in hospice, Medicare will cover the cost of up to five days in a row of respite care at a hospital, in-patient facility, or nursing home. You can receive this free respite care more than once, but only on an occasional basis. Ask your hospice care provider about your options.

The VA

If you are a U.S. military veteran who qualifies for service-connected benefits, you should be eligible to receive caregiving services at no cost. Ask about your respite care benefits.

Long-term Care Insurance and Medicaid

If you purchased long-term care insurance before your diagnosis, or if you qualify for long-term care through your state's Medicaid program, you may be eligible for a certain number of professional caregiving hours per month.

Get Local Support



ALS United North Carolina
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