

Florida Respite Care for ALS Caregivers FAQ

WHAT DOES THIS PROGRAM OFFER?

This program provides all families with an overview of respite care, why it is important and what options are available. For those caregivers in Florida who need financial support to hire in-home support, a grant may be available through this program.

WHAT IS RESPITE?

Respite simply means an interval of rest or relief. Respite gives you, the family caregiver, an opportunity to take a much-needed break from the daily care that you provide for your loved one. There are many ways you can spend your “time off” during your respite. Going to movies, reading a book, taking a nap, treating yourself to lunch at a restaurant, taking a walk, getting your hair cut, or attending a caregiver support group are some examples. Anything that helps you to rejuvenate or care for you.

WHO IS THIS PROGRAM FOR?

This program is for persons caregiving for someone with ALS in Florida. Individuals must be registered with the ALS Association. This grant program is designed to provide respite to full-time caregivers who live in the same household as the person living with ALS. One application per family will be accepted annually.

WHAT MAKES ME INELIGIBLE TO APPLY?

Individuals receiving care and/or benefits through the following programs are not eligible to apply:

- Individuals who live in a skilled nursing facility;
- Veterans receiving service-connected benefits;
- Individuals receiving care through Florida’s Statewide Medicaid Managed Care – Long Term Care Program.

HOW MUCH FUNDING WILL I RECEIVE?

Grants will be awarded at \$2000. This is estimated to provide approximately 60 hours of in-home support. This is based on an hourly rate of approximately \$33. The hourly rate of service will vary greatly on geographical area and type of care required.



WHAT TYPES OF SERVICES CAN I USE THE FUNDING FOR?

Award recipients will receive a \$2000 grant to allow them to hire respite services through either "self-coordinated" or "agency":

- "Self-coordinated" - Families may choose to contract with an individual of their choice, other than a family member.
- "Agency"- Families may select a home care agency to provide a professional caregiver. The ALS Association staff may assist in providing options based on where the person with ALS lives.

Hiring of certified nursing assistant (CNA) or home health aide (HHA) is encouraged, while not required.

HOW WILL SERVICES BE PAID FOR?

Grant recipients are responsible for hiring, coordinating visits, and paying for services. Informational resources will be shared to guide you through this process.

WHEN DO I HAVE TO USE THE FUNDING?

We ask that you use your funds within 6 months of receiving the funding.

HOW CAN I APPLY?

Visit [ALS.org/Florida-Respite](https://www.als.org/Florida-Respite) to complete the application. Applications are reviewed and awards are granted two times per year. One application per family will be accepted annually.

IF I AM AWARDED, WHAT IS REQUIRED OF ME?

- Participate in a 45-minute orientation (will be available recorded) about the program and helpful tips in hiring respite services.
- Utilize funds within 6-months of award grant receipt.
- Complete two surveys at 3-month and 6-month point to provide feedback on accessing respite services. Your feedback will be helpful as we look to expand respite programming for ALS families.
- Submit receipts and/or a time log for respite services at the end of the 6-month award period.

WHAT IF I AM UNHAPPY WITH THE RESPITE SERVICES I'M RECEIVING?

You may discontinue service with one company or individual and hire a new company or individual. We ask you to use the funds within 6 months of receiving the grant.



WILL I ALWAYS HAVE THE SAME CAREGIVER IF I GO THROUGH AN AGENCY?

When utilizing a home care agency, consistency with caregivers is always the goal. That said, home care agencies cannot guarantee certain paid caregivers every time. Changes in schedules, staff turnover, and vacation/sick days all play a part in the options an agency has for staff at any given time. The best way a family can maximize the likelihood of consistency with paid caregivers is to be consistent with using the service. If family caregivers choose the same day and time each week to utilize home care services, there is a higher likelihood of seeing the same paid caregivers.

WHAT WILL HELP MAKE OUR RESPITE EXPERIENCE SUCCESSFUL?

- The more flexible you are, the more options the agency will have to staff your in-home support.
- Realistic expectations are important!
- Understand that home care support is not an on-demand or on-call service and is not for emergencies.

IF YOU HAVE ANY QUESTIONS ABOUT THE PROGRAM, CONTACT JACKIE KOURI-MATHEWS AT JACKIE.KOURI-MATHEWS@ALS.ORG.

