

The ALS Association's Jack Norton Caregiver Respite Program FAQs

Q: Who is this program for?

A: This program is for the live-in caregiver of someone with ALS in North Dakota & South Dakota.

Q: Do all caregivers qualify for the family respite program?

A: Caregivers who qualify for respite are the ones who live with the person with ALS and are considered the full-time caregiver.

Q: Can the caregiver respite program be used to help care for someone with ALS?

A: This program is about providing *a respite or break to the family caregiver*. It is not designed to be *relied upon to provide care needs to the person with ALS*. Rather, it is meant to supplement the complete, all-inclusive care that the person with ALS is receiving from their family caregiver.

Q: How many respite hours are available to the family caregiver?

A: The respite program offers weekly respite in 3-4 hour increments, not to exceed 18 hours each month.

Q: What if the family caregiver doesn't use all of their respite hours each month?

A: Family caregivers receive a new 18 hours each calendar month. If the full 18 hours are not used, they do not roll over into the following month.

Q: Who provides the actual respite in the home?

A: The respite service is provided by health care professionals employed by one of The ALS Association's partnering agencies. These health care professionals are usually not nurses, but rather home health aides, Certified Nursing Assistants (CNAs), or Personal Care Assistants (PCAs). The respite caregivers are employed by the home care agency, not The ALS Association.

Q: What kind of qualifications do the respite caregivers have?

A: Home Health Aides, Certified Nursing Assistants (CNAs) and Personal Care Assistant (PCAs) all receive on-the-job training via the home care agency they work for. They all receive background checks as well.

Q: Can the family caregiver choose the home care agency they want to work with?

A: The home care agencies that are partnered with The ALS Association belong to a small network of vetted agencies that receive ongoing information and training from the ALS Association about ALS and the respite program. There are written agreements with each agency that establishes pay rates and other negotiated services. Putting these partnerships in place streamlines our relationship with our partnering agencies, creates more accountability for excellent service and helps the ALS Association be a good steward of donor dollars.

Q: What if a family is working with a home care agency different from the ones that the caregiver respite program partners with?

A: It is not uncommon for someone with ALS to be receiving some type of service in their home from any given home care agency. Many people with ALS, for example, might qualify for temporary, skilled Medicare-covered services. These services are generally short-term and intermittent, continuing to the point when a specific Medicare-related goal has been met.

A person with ALS might also be getting in-home care through another payer such as long-term care insurance, Medicaid, or the VA. Some families also choose to privately pay a particular agency for services in their home.

It is okay, and not that uncommon, to receive multiple services, reimbursed by multiple payers, through multiple providers in the home. In fact, “widening the net” of available staff to meet the needs of someone with ALS at home often results in a higher likelihood to get those needs met.

Q: Can respite services continue even if the person with ALS is on hospice?

A: Yes.

Q: Can caregivers of veterans access the family respite program?

A: Yes. We ask that veterans first maximize their VA home care and caregiver respite benefits prior to their caregiver applying for the Family Respite Program.

Q: What kind of things can the respite caregivers do while they're in my home?

A: A respite caregiver is primarily there to make it so the family caregiver can leave the home and know that their loved one with ALS is being safely attended to. While there, a respite caregiver can assist the person with ALS with ‘Activities of Daily Living’. The respite caregiver may also be able to provide some light housekeeping that pertains to the cares they are providing the person with ALS and involves the areas of the home that the person with ALS occupies. **Respite caregivers are not professional housekeepers.**

Q: Are there certain cares a respite caregiver cannot provide to my loved one with ALS?

Yes, there are limitations to the types of cares that can be provided, such as feeding tube cares, medication administration, deep suctioning, and adjusting air pressure on a bi-pap or trilogy machine. There may also be situations where it is determined that a person with ALS needs the assistance of two people to safely transfer. These situations are determined on a case-by-case basis and solutions/options will be presented to you by the home care agency.

Q: Why does it have to be a 3-4 hour shift?

A: Home care agencies generally need to send their employees to the homes of people for at least 3 or 4 hours at a time in order for it to be cost-effective. This is why it is most common for family caregivers to use the respite once a week for a 3-4 hour shift.

Q: Will we always have the same respite worker coming to our home?

A: Consistency with respite caregivers is always the goal. That said, home care agencies cannot guarantee certain 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 respite caregivers is to be consistent with using the service. If family caregivers choose the same day and time each week to take their respite, there is a higher likelihood of seeing the same respite caregivers.

Q: Does a family caregiver need to leave the home while using respite?

A: No. A family caregiver can go into another room and rest or read. Some family caregivers spend their respite time outside in the yard or garden. The intention of this program is for a caregiver to recoup from caregiving, and there are many ways to accomplish that.

Q: Can a family caregiver go to work while using respite?

A: Because the caregiver respite program is more about giving the family caregiver a break from caregiving than it is about trying to use the limited hours for filling in care gaps, it is not recommended that the family caregiver attempt to use the respite hours so that they can work.

Q: Will I get a bill for respite?

A: You should not get a bill for respite hours. The only exception to this would be if the family is paying the home care agency to provide additional care hours in the home. If you accidentally receive a bill from your respite agency, simply let them know of the error. If questions, you can always contact the ALS Association.

Q: How much does respite cost?

A: Respite costs vary depending on the rates the ALS Association has been able to negotiate with each agency we partner with. Some agencies are willing to contract a lower rate, particularly if they serve multiple ALS families. Some agencies are also able to waive costs for nursing assessments and supervision, which can be a large cost savings. The average hourly cost of the respite service is between \$40-\$50 per hour.

Q: Why do I need to complete an application to use the caregiver respite program?

A: The application to our caregiver respite program serves a number of purposes. It is used to provide the home care agency with the most up-to-date information about the needs of your loved one with ALS. *For this reason, it's important to complete the application as close as possible to the time that you are ready to use it.* The other purpose of the application is to serve as a release of information form that allows the ALS Association and the home care agency providing respite to share information back and forth allowing for the necessary communication and collaboration to best serve you and your loved one through this program.

Q: What are the steps that are taken to get respite started in my home?

A: Respite Intake: This is usually a 30-minute phone call or zoom meeting with the respite program manager to discuss the program parameters, your questions, and next steps.

Respite Referral: The respite program manager contacts one of the partnered respite providers to ensure that they are able to provide weekly respite. Once a home care agency is secured, the program manager sends the referral and authorization to the agency.

Nursing Assessment: Once the agency receives the referral they will contact the family caregiver to schedule the in-home nursing assessment. Following the assessment, the family caregiver will be in communication with the agency's staffer to schedule their respite time.

Q: What will make my caregiver respite program experience the most successful?

A:

- The more **open & flexible** you can be about when you use your respite time, the more options the agency will have to make the best staffing match possible.
- The more **consistent** you are with when you schedule your respite time (same time each week), the more likelihood there is for consistency in respite caregivers.
- Realistic expectations** are important! Understand that respite is **not an on-demand or on-call service** and is **not for emergencies or finding coverage for care needs**. It's for deliberate, scheduled time away for the family caregiver. When scheduled for this reason, unexpected disruptions in service, while inconvenient, will be less problematic.

Q: What about COVID-19?

A: Families need to decide for themselves whether or not they feel comfortable having additional people in their homes and caring for the person with ALS. Home care agencies have policies in place to protect their staff and the people they serve. Agencies utilize PPE (personal protective equipment), hand washing, and are told not to come to work if they have symptoms or have known exposures. A family's decision about whether to use the ALS Association's Jack Norton Caregiver Respite Program depends on whether the need for respite outweighs the risks.

***Agencies are not able to disclose whether or not their employees have been vaccinated.**