

Home Care (non-medical)

Home care is non-medical care that is provided in the home by paid caregivers who are either independent or employed by a home health care agency. Home care can include assistance with daily activities like transferring, bathing, toileting, dressing, grooming, and eating. It can provide much-needed breaks for primary family caregivers.

When looking for home care, you'll need to decide whether you want to hire an independent caregiver or go through an agency with caregivers on staff. There are pros and cons to each option.

Hiring an independent caregiver is usually less expensive, but you will need to find and interview candidates, conduct background checks, check references, and be in charge of scheduling, paperwork, taxes, and potential liability concerns. You will also need to resolve any issues or disputes yourself. It is usually a good idea to have a backup option for the times when your caregiver may be sick or take vacation time.

The other option is to hire a home health care agency that will send paid caregivers, sometimes known as home health aides, to your home on a predetermined schedule. Agencies are usually more expensive and may require a minimum number of hours, but they will take care of the paperwork, liability, logistics, backup coverage, and any issues that may arise. Rates will vary by agency and location.

Finding a Paid Caregiver

Selecting the right person or agency is very important. It is worth doing research up front and conducting a thorough interview process to make sure you find the right match. Begin by asking your ALS clinic, Care Coordinator with ALS United NC, family, and friends for recommendations.

Interview at least two or three individuals or agencies. When researching agencies, look for online reviews, number of years in business, and whether they are licensed and insured in your state. Before interviewing agencies, it can be helpful to make a list of questions such as:

- Do your caregivers have experience working with ALS clients?
- How will you train your caregivers to work with an ALS client?
- Do you have caregivers who are strong enough for transferring?
- How will you communicate with family members?
- Do you require a minimum number of hours per visit or week?
- How many regular caregivers will you send?
- Will you always be able to provide backup coverage?

Hiring a paid caregiver or home health aide can be expensive and is not usually covered by insurance. You will likely need to pay out of pocket unless:

- You qualify for long-term care through your state’s Medicaid program
- You purchased a long-term care policy before your ALS diagnosis
- You qualify for assistance with a short-term assistance respite program
- You are a U.S. military veteran with service-connected benefits

Train and Support Your Caregivers

Levels of training and experience vary among paid caregivers. Some may just have experience helping with activities like bathing, dressing, and meal preparation. Others will have more formal training and can perform more advanced tasks. It is important to ask your caregivers and/or agency what they know how to do and what they are and not allowed to do.

You will need to help train and support your paid caregivers, especially in the first few weeks. Even if your caregiver does have experience with ALS, every individual and situation is unique.

If you are currently using any medical equipment, you will want to take time to teach your caregivers how to use each device. If you feel your caregivers need more formal training than you can provide, ask your ALS clinic team or neurologist for suggestions.

When you are paying someone to provide care in your home, you should be very happy with the quality of service that you receive. If you feel unsatisfied, uncomfortable, or untrusting—for any reason—you have the right to speak up, and change caregivers if needed.

Get Local Support



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