

Caring for someone with ALS

Taking care of a person with **amyotrophic lateral sclerosis (ALS)** is challenging on many levels. However, with the right mindset, support from others, and proper assistive devices, it can also be fulfilling.

Empower yourself with knowledge

By understanding why the person you are caring for cannot move well, has muscle twitches and spasms, experiences pain and excessive drooling, and later has difficulty feeding and breathing, you will be able to better predict the problems your loved one has and can prepare well for those transitions.

Seek support

The physical demands of caring for someone with ALS are vast and range from assistance with activities of daily living to managing mobility aids and eventually feeding devices and breathing machines.

Seeking support from others is therefore essential. You should start with your loved one's ALS healthcare team, which includes a neurologist, physical therapist, speech and swallow therapist, nutritionist and a respiratory therapist, and also approach a local community centre.

Assistive devices

Muscle weakness is a primary symptom of ALS, and with that comes such problems as the inability to walk, eat and keep the head upright.

Assistive devices, e.g. wheelchairs, bathtub lifts, raised toilet seats, removable headrests, and special eating utensils can improve the ability to function and the quality of life for a person with ALS.

Other useful devices include special mattresses that can help prevent skin breakdown, or electronic communication devices.

Respite care

As a caregiver, you need to look after your mind and body to best tend to someone else's health. In other words, you **need breaks**, and this is where **respite care** comes into play. Respite care may mean a few hours off to enjoy a movie, take a nap, or go out to dinner or coffee with a friend.

You can also look into home health agencies that provide trained caregivers or even a residence that employs healthcare professionals on-site. Lastly, you can opt to simply ask a friend or volunteer agency to provide respite care for a few hours.

Watch for symptoms of depression

Caring for someone with ALS may be linked with a range of emotions including worry, frustration, and/or even anger. Many caregivers also feel guilt or uncertainty about the future.

Sometimes these emotions can be so strong and persistent that they begin to affect the caregiver's quality of life and turn into depression. Symptoms of depression may include:

- Feeling sad or down
- Experiencing a loss of interest in activities you once enjoyed
- Having sleeping difficulties (e.g., sleeping too much or having trouble falling asleep)
- Having a change in appetite
- Feeling guilty or hopeless

The good news is that depression can be treated, either with a combination of medication and talk therapy, or one of these treatments alone.

Caring for a person with ALS is difficult and energy-consuming, both physically and mentally. In the end, your care, your attention, and your presence are enough. So be kind to yourself and remember to be mindful of your own needs.

Adapted from: <https://www.verywellhealth.com/caring-for-a-loved-one-with-als-4154624>