

Advocating for Yourself

Even when you have support from an ALS clinic or medical team, you will need to be in charge of your own care. You and/or your caregiver will need to schedule your appointments, apply for benefits, seek out resources, communicate your needs, and ask questions when you don't understand something.

You are the only ones who truly understand your situation, so you will need to communicate important details with your medical team and everyone else. All of this responsibility can feel overwhelming, but being proactive and advocating for yourself can help you get the best care possible, save money, and have a better quality of life.



Educate Yourself

It is important to educate yourself and your loved ones about ALS and what may lie ahead on your ALS journey. It is helpful to understand what your needs may be ahead of time so you will know what to expect and which questions to ask.

Get Organized

Developing an organizational system can help you feel less overwhelmed and more in control of your situation. Having one place where you keep all your lists, notes, records, and information can be helpful for everyone involved in your care.

Reach Out and Ask Questions

Three months between clinic visits may feel like a very long time. If your symptoms change or any questions or concerns arise between visits, contact your ALS clinic coordinator or medical team.

Take and Share Notes

It is helpful to take notes during your appointments and meetings. If possible, ask someone to accompany you to take notes and ask questions if needed. After your visits, you may want to share updates with anyone else involved in your care. It is also important to write down questions or concerns between visits so you will remember what to ask on the next visit.

Apply for Benefits

If you stop working, you will want to apply for Social Security Disability Insurance and Medicare benefits right away. It is best to understand your health insurance options ahead of time.

Be Smart about Equipment

Getting the right equipment at the right time can improve your quality of life and even help you live longer. Most of your equipment costs should be covered by Medicare, Medicaid, and private insurance, though you may still need to pay for some expenses out of pocket.

If you cannot afford expenses for equipment you need, talk with your durable medical equipment (DME) provider and/or ALS Arizona about financial assistance options. Before purchasing any piece of equipment, always ask if you can borrow it at no cost from a local equipment loan closet.

Plan Your Care and Support

Caring for a person living with ALS can be challenging, especially as the disease progresses. Family caregivers often struggle to care for their loved one while juggling the demands of daily life. Finding additional help can allow the relationship between you and your loved one to be more than just patient and caregiver.

Skilled nursing care and therapy services are usually covered by insurance, but general assistance with daily living care like bathing and toileting is not. If you cannot afford to pay for professional caregiving services out of pocket, you can reach out to your family, friends, and community to help with care and support. It can be hard to ask for and accept help, but it is an important part of creating a more balanced and sustainable long-term plan.

Make Important Decisions Ahead of Time

When living with ALS, there are some very important medical decisions you will need to make, such as whether you want a feeding tube and whether you want a tracheotomy. These can be difficult topics to think about, but many people actually feel peace of mind once they make these important medical decisions ahead of time and fill out their advance directives.

Get Local Support

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