



AN ALSP GUIDE FOR
Caregivers and
Family Members

Becoming a Caregiver and an Advocate for Your Loved One with ALS

A diagnosis of adult-onset leukoencephalopathy with axonal spheroids and pigmented glia (ALSP) affects the individual and their entire family. This resource can help guide family members who are looking for ways to support their loved one with ALS and family members who are at risk for ALS.

ALS is a rare genetic disease caused by a defect in the DNA (mutation) of the *CSF1R* gene. ALS is progressive, which means that symptoms impacting an individual's memory, thinking, behavioral, psychological, and physical abilities will become more severe over time and a caregiver's role will continue to evolve. A loved one living with ALS will eventually require full-time support for personal care and medical management. Being a caregiver for a loved one with ALS is a difficult journey, but there are ways to help make it a period of time that can be manageable and fulfilling.

Please remember, there are many ways to provide love, care, and support to your loved one. The right approach is the one that works best for those who are involved. Consider this guide a starting point. All of the following information was compiled based on advice from individuals living with ALS as well as their families and caregivers. If you are searching for ways to provide support, this guide contains several suggestions for things that you can begin to do today.



Being empowered is advocating for your loved one and also finding a care team that can speak to you with an open mind.

- Catherine, ALS Caregiver

1. Learn about ALSP and provide initial support.

Receiving the initial diagnosis of ALSP can be devastating and isolating. Learning about the disease can be empowering for you and your loved one. Understanding the disease can enable you to help your loved one process their worries and concerns and determine their next steps. Being involved in the beginning is meaningful and can help both of you feel less alone.

2. Research the disease and its treatment options.

It can be beneficial to look into ongoing research and available clinical trials. Through education and outreach, you and your loved one will be able to make informed decisions. Health care providers should be your main points of contact for information and advice, but other helpful resources include “A Guide for Understanding ALSP,” ALSPinfo.com, SistersHopeFoundation.org, and ClinicalTrials.gov.

3. Assist in building your loved one’s health care team.

It can be difficult to find doctors who know about ALSP and having a doctor who is open and wants to learn more about ALSP might be the best approach for you and your loved one. There are doctors who have experience with ALSP, and if resources and care goals align with the required time and travel then it could be worth it to seek them out. Keep in mind that there is no right approach to care: one that feels right for you and your loved one is the best choice.



If speaking with an ALSP expert is important to you and your loved one, there may be travel assistance opportunities available through advocacy groups such as Sisters’ Hope Foundation.



Locate Experts

The following health care centers are focused on ALSP in the United States. Email patients@vigilneuro.com for additional information and other centers:

Mayo Clinic
Jacksonville, FL

Massachusetts General Hospital
Boston, MA

University of Pennsylvania
Philadelphia, PA

4. Participate in discussions with health care teams.

Support your loved one by actively participating in conversations with health care teams. This can mean leading the dialogue, taking notes or handling communications with doctors and other providers, such as insurance companies. Make sure that you and your loved one are on the same page about your participation.



Questions to ask doctors

There are no questions that are off limits when it comes to your loved one's health. Don't hesitate to ask hard questions, obvious questions, or even the same question twice. Asking the right questions can further personalize care and prepare both of you for the future. Consider the examples below when preparing for a future appointment:

- **Who should be our primary care provider?**
Is it okay to work with our current primary care provider?
- **How often should we see our doctors?**
- **What are our goals for disease management?**
How will our goals change over time?
- **What supportive care and therapy should we consider?**
- **What should we be doing now to prepare for the future?**
- **Can you help me identify ongoing research and clinical trials for ALSP?**



Tips for staying organized

This can be an overwhelming time and you may have other responsibilities, too, including caring for children and working full-time or part-time. To minimize stress, it can be beneficial to stay organized.

Keep an ALSP binder or journal with information about the disease and your loved one's care. Within those materials, consider cataloging the following information:

- ✓ **A calendar** of health care appointments
- ✓ **Printed findings** from the latest research
- ✓ **Test results** arranged in order
- ✓ **A journal or tracker** with your loved one's symptoms between appointments
- ✓ **Notes** from appointments
- ✓ **All questions for doctors** that come up after visits



I started to keep a folder to keep everything in—from articles to notes from appointments; it's really helpful to have it all in one place.

- **Serena**, *CSF1R* carrier

5. Take steps to become your loved one's proxy.

ALSP is a progressive disease that impacts your loved one's memory, understanding, thinking, behavior, mental status, and physical abilities. While every individual's symptoms present differently, most will experience a decline in health as ALSP advances over time. Eventually, individuals will not be able to manage activities of daily living and will need full-time care.

Looking to the future is difficult, but those living with ALSP and their caregivers may want to proactively discuss health care, finances, and end-of-life wishes and complete legal documents that allow caregivers to make decisions. By doing so, you can leave more time to enjoy each other's company and everyday moments.



Having gone through this with five family members, I can share that the last year of their life will be tough and challenging. Setting things up properly will allow you to enjoy the best of these moments with your loved one.

**-Heidi, ALSP Caregiver
Founder, Sisters' Hope Foundation**



Questions to ask your loved one

There will come a time when your loved one may not be able to communicate their wishes as it relates to medical and personal care. Discuss your loved one's goals and values early on but also maintain an open dialogue to understand if their priorities change. Below are some questions to ask before formulating a plan:

- What aspects of your health and well-being are essential to you?
- What are your goals for your care?
- How would you like family members and friends to be involved?
- How would you define a good quality of life?
- Do you understand the course of ALSP and how it might affect you and your abilities?
- What support do you feel you need now? What do you think you might need soon?
- Do you have a living will?

6. Prepare to champion your loved one's care in the future.

As ALSP progresses, your role as a caregiver will evolve. In the beginning of an ALSP diagnosis, your loved one will most likely need your love and support while navigating a future with ALSP. As the disease advances, you will need to manage medical and personal care. Medical management can include scheduling appointments, recording symptoms, administering medications, and communicating with providers. Personal care means bathing, grooming, dressing, toileting, shopping, preparing meals, housekeeping, and assisting with exercise, mobility, and transportation.

Most family members aren't sure when to start providing support in certain areas and assume a more active caregiver role. **A neuropsychological evaluation and assessment can be useful in defining care needs.** Reach out to your loved one's doctor for support; they can recommend an evaluation and also help you understand when it might be appropriate to make changes.

Please know that you are not alone. Enlist the support of friends and family. You may find that many people want to help you, they just need to know how. **Make a list of support needs and share it with friends and family.** Helpful assignments for willing family members and friends can include asking them to take over grocery shopping, meal preparation, housekeeping, and transportation.



Further reading for caregivers

Caregiver resources provide more guidance as you learn to become your loved one's advocate and navigate other aspects of your role as a caregiver.

Find information about day-to-day caregiving tips and resources, finding financial support, how to take care of yourself as a caregiver, and more through the following organizations:

Caregiver Action Network
caregiveraction.org

Today's Caregiver
caregiver.com

The Caregiver Space
thecaregiverspace.org

Well Spouse Association
wellspouse.org

Sisters' Hope Foundation Support Groups
sistershopefoundation.com/events

Talking to Family Members About ALSP

ALSP is a genetic disease caused by a mutation to the *CSF1R* gene and each person with the mutation has a 50 percent chance of passing it on to their children. An ALSP diagnosis can cause concern for family members about their own health and future.

While the decision to pursue genetic testing is difficult, getting tested as early as possible can allow individuals and families to do the following:

- **Make decisions about life priorities and family planning**
- **Plan financial decisions based on potential future care needs**
- **Have the opportunity to participate in genetic research and clinical trials**

Guidance on Genetic Counseling

Open and honest discussions about genetic testing are not easy, but they are important. Certified genetic counselors can guide conversations, provide education about genetic risks, and explain the genetic testing process. However, seeing a genetic counselor does not mean that you or your loved ones have to get tested. A meeting can be an opportunity for you and family members to feel more informed before making any decisions.



The role of the genetic counselor is to help counsel individuals about their genetic risk and considerations for testing. However, talking to a genetic counselor does not mean that an individual needs to be tested. A genetic counselor is a great resource for individuals looking to talk and learn.

- Tanya, MS, Licensed Certified Genetic Counselor (LCGC)



Questions to ask a genetic counselor

- ALSP is genetic and can be passed through family members, can you explain what that means for our family?
- Why would I want to understand our risks of having inherited the genetic mutation?
- What would finding out about having the genetic mutation mean for me?
- What is the value of knowing that I have the genetic mutation? What are the risks of not finding out?
- At what age can I get tested?
- What is the process for testing and how long does it take?
- How can test results impact others in my family? How can I talk to others in my family about results?

Talk to your doctor about how to find a genetic counselor and to receive a referral. Many genetic counselor appointments and tests are covered by insurance.

If you or others in your family decide to pursue genetic testing, ask your doctor about a sponsored genetic testing program called “Detect Leukodystrophy.”

For more information, visit: [invitae.com/en/leukodystrophies](https://www.invitae.com/en/leukodystrophies)

ALSP Community Connections



ALSP is a rare disease but you are not alone.

Approximately 10,000 people in the United States, 15,000 in Europe, and 4,000 in Japan are affected by ALSP. Connect with the ALSP community and learn about the disease by visiting the following:



[ALSPinfo.com](https://www.alspinfo.com)

[SistersHopeFoundation.org](https://www.sistershopefoundation.org)

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