



Navigating Your ALS Diagnosis

A helpful guide to
moving forward on
your treatment journey





FINDING YOUR WAY FORWARD

Learning that you or a loved one has amyotrophic lateral sclerosis (ALS) can be hard to process. There has been a lot for you to learn and many decisions still to be made. Every ALS journey is different, so it's normal to feel unsure about what comes next.

This guide is here to help. It explains what ALS is, introduces the people who may be part of your care and support team, helps with planning for now and the future, and offers resources to guide you along the way.



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Understanding ALS

What is ALS?

Amyotrophic lateral sclerosis (ALS) is a disease that affects the parts of your nervous system that control your muscles, like those used for speaking, eating, moving, and breathing. It is progressive, which means the symptoms continue to get worse over time. ALS symptoms can be very different for different people based on which parts of the body are affected first. You may have heard ALS referred to as Lou Gehrig's Disease.^{1,2}

How do I say it?

amyotrophic → ay-my-uh-TROH-fik | lateral → LAT-uh-rul | sclerosis → skluh-ROH-sis



There are 2 kinds of ALS¹

Genetic ALS

- Those with a family history may be more at risk of getting ALS
- Caused by mutations in genes passed down through families

Sporadic ALS

- Makes up **90%** of all ALS cases
- Happens at random
- Is not connected to having a family history of the disease

The focus of this guide will be on sporadic ALS.

[Learn more about what ALS is and who it affects](#)

How ALS affects the body

ALS starts in the brain and spinal cord. It affects nerve cells called motor neurons. These cells send messages from the brain to the muscles that control movements like walking, holding objects, talking, swallowing, and even breathing.¹

In ALS, these messages stop being sent and the brain loses control of the muscles, making it hard to move and stay independent.¹

Not everyone will have the same symptoms

ALS symptoms can happen at different times for different people. However, over time, most people with ALS will feel muscle weakness and experience loss of movement.^{1,2}

[Click here](#) to find helpful resources for living with ALS



ALS looks different for everybody, but some symptoms may include^{2,3}:



Head and neck

- Trouble speaking
- Too much saliva
- Hard to swallow



Lungs

- Shortness of breath
- Breathing problems
- Waking at night because of breathing difficulties



Upper body

- Weak hands
- Can't move your arms easily
- Muscle spasms in your upper body
- Trouble getting dressed or with personal hygiene
- Difficult to write
- Hard to make food



Lower body

- Tripping often
- Stairs are hard to use
- Weakness in feet

The Importance of Early Treatment

ALS clinical studies use a tool called the **ALS Functional Rating Scale–Revised (ALSFERS-R)** to track how ALS is progressing. It uses points to measure changes in a person's ability to do activities including but not limited to³:

- Speaking
- Cutting and eating food
- Climbing stairs
- Breathing without help

Your doctor may or may not use the ALSFRS-R with you, but it is sometimes needed for insurance coverage purposes.

In total, a person can have 48 points on the ALSFRS-R. **On average, someone with ALS may lose about 1 point per month.**^{3,5}

[Learn more about helpful interventions for trouble chewing, swallowing, and breathing](#)

What could point loss mean for your independence?

Losing just **1** point could be the difference between³:

Eating on your own → Needing help being fed

Getting tired walking up the stairs → Having someone to help you

Having some trouble getting dressed → Needing help or using adaptive clothing



Starting treatment early

Right now, there is no cure for ALS or treatment that can undo the impairment it has already caused. However, there are 2 FDA-approved medicines for sporadic ALS a doctor can prescribe at the same time.¹

[Learn more about a treatment option](#)

Finding Your Care Team

Leaning on a team of specialists

Treating ALS takes a village. That's why multidisciplinary teams are made up of many different people who specialize in different areas of care. That way, they can create a care plan that is tailored to you or your loved one's needs.¹

Together with your care team, you can focus on staying mobile, comfortable, and independent for as long as possible.¹



Your care team

Often, ALS multidisciplinary care teams include specialists such as⁶:

✓ **Doctors**

✓ **Social workers**

✓ **Nutritionists**

✓ **Pharmacists**

✓ **Clinical psychologists**

✓ **Clergy members**

✓ **Physical therapists**

✓ **Occupational therapists**

✓ **Speech therapists**

✓ **Respiratory therapists**

✓ **Home care and hospice nurses**

[Download](#) the *Keep Track of Your Healthcare Team* tool



Tips for Managing Life With ALS

After an ALS diagnosis, it can feel like there are endless decisions to be made. Remember, you don't need to have everything figured out right away. Some things can wait so you can focus on priorities and just coping with your new day-to-day life.

What you can plan for now

- ☐ Talk to your doctor about a possible treatment plan

- ☐ Make a plan for managing your mental health (eg, through counseling, exercise, or socializing)

- ☐ Create weekly or monthly goals for yourself

- ☐ Stay social with friends and family

Considerations for the future

As ALS progresses, there are ways to prepare to meet your changing needs. Planning ahead for changes before they happen can give you a better sense of control.⁷



Find adaptive clothing designed to make dressing and using the bathroom easier (eg, slip-on shoes, front-clasping bras, clothing with magnetic buttons)⁷



Make accessibility adjustments to your home (eg, adding a shower seat, reorganizing closets and cupboards to keep well-used objects in reach, or installing ramps and support bars)⁷



Practice how to use mobility devices before they are needed (eg, canes, walkers, or motorized wheelchairs)⁷

Navigating ALS as a Care Partner

Supporting your loved one

As a care partner, there are many ways you can support your loved one through their ALS journey. Every situation is different, but care partner duties often include helping with:



Emotional support⁸

- Being someone your loved one can talk to about how they're feeling



Daily activities⁹

- Getting dressed
- Personal hygiene
- Eating



Treatment⁹

- Setting up and going to appointments
- Giving medications
- Managing insurance coverage



Household to-dos⁹

- Grocery shopping
- Household chores
- Preparing meals

Communicating openly with your loved one about what their needs are now and understanding how they will change over time is an important part of providing care.

Caring for yourself

Becoming a care partner can be a big and sudden change in your life. It's important to remember that you have emotional and physical needs too. Caring for yourself helps you provide the best care for your loved one.



Make time for yourself to enjoy a hobby



Connect with other care partners through support groups



Lean on friends and family for day-to-day support

It is okay to feel guilt and anger when things are overwhelming. These are normal reactions to being in a very hard situation. Be kind to yourself and recognize that you are doing your best and that is enough.



[Learn how to cope with feelings of burnout](#)

Children and the ALS journey

When a parent or loved one is diagnosed with ALS, children and teens often play a big part in daily care. They may help with basic medical needs, provide emotional support, share in household chores, help with hygiene tasks, or care for siblings.¹⁰

It's important to support the overall well being of a young carer. Access to mental health, school-based, and family support can help ease stress. Recognizing their role—and how caregiving may affect things like school performance and relationships—can help reduce challenges and support positive involvement in care.¹⁰



Young carers of a person with ALS spend **an average of 5 hours a day** doing care tasks.¹⁰



To help young children understand ALS with compassion and honesty, consider watching the [Luki & The Lights](#) short movie by YCare

Building a strong support network

You have more help than you may realize. Between friends, family, spiritual communities, colleagues, teammates, and neighbors there are people in your life who will want to lend a hand where they can.

To make the process of delegating tasks easier, try writing the following lists:

List 1

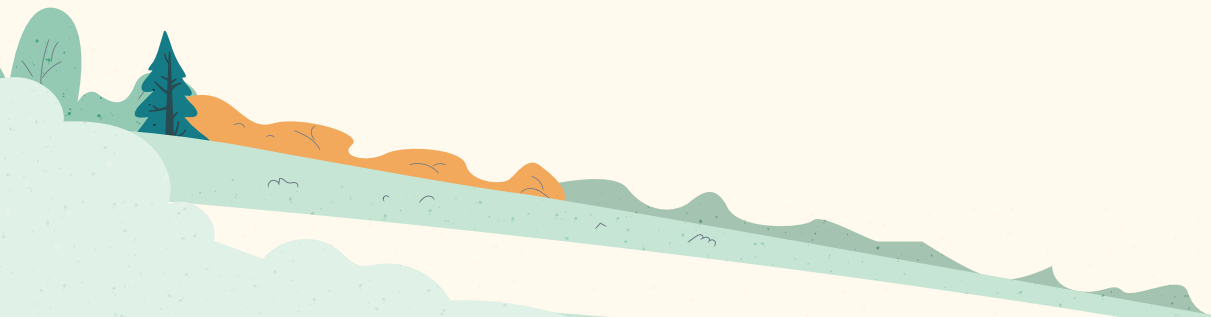
Tasks that you are
comfortable giving
to someone else

List 2

People who have
either offered help
or who you feel you
can ask for help

Compare your lists. Who is best suited for each task? You may have a neighbor who can cut your grass or a friend with the skills to do repairs or help make accessibility upgrades to the house (eg, handrails or ramps).

If you're unsure, just ask the people in your life which task(s) they would like to help with.



Navigating Financial Roadblocks

Understanding coverage denials and appeals

After you and your doctor decide on an ALS treatment that's right for you, you may struggle with navigating how to get your costs of care covered. This can be a frustrating process but getting a denial for coverage is not the end of the road.

What is a denial?¹¹

An insurance provider might say no to paying for medication, specialized care, or equipment.

If they reject your claim, they will send a denial letter to you and your doctor explaining why it was denied and how to submit an appeal.

What can you do about it?¹¹

Your doctor will have the opportunity to challenge a denial for you. The goal of an appeal is to ask your insurance provider to change their decision so that you can get the care your doctor has confirmed you need.

If you receive a denial letter, follow up with your doctor's office so they can start the appeal process.

For your best chances at appealing a denial, your doctor will send information showing that the care you need is¹¹:

☒ **Necessary** ☒ **Safe** ☒ **Effective** ☒ **Reasonable**

[Read more about appeals and denials](#)

Resources to Help Guide You Forward

Feel prepared for the journey ahead

There are many resources available to help but it can feel overwhelming to decide where to turn next. It's helpful to be aware of what resources exist and go back to what's most helpful for you when you are ready.

[ALSPathways.com](#)

Navigating your ALS journey

[Global Neuro YCare](#)

Supporting children as young carers

[ALS Pathways Podcast Series](#)

Offering important insights into life with ALS

[True North Men's Group](#)

Connecting with other men living with ALS

[ALS Insurance Navigator™](#)

Understanding insurance denials and appeals

[Her ALS Story](#)

Finding support as a woman diagnosed under 35

[ALS Association Certified ALS Centers and Clinics](#)

Finding an ALS clinic near you

[Hope Loves Company](#)

Offering support to children who have or had a loved one with ALS

This is not an exhaustive list of resources. Other than ALS Pathways, Shionogi Inc. does not endorse any particular service or group and is not responsible for the content of these sites. These resource organizations are provided for informational purposes and are not meant to replace a doctor's medical advice.

Navigating your ALS Diagnosis

When an ALS diagnosis leaves you feeling lost,
finding your path forward is still possible.

Visit [ALSPathways.com](https://www.alspathways.com)

References: 1. Amyotrophic lateral sclerosis (ALS). National Institute of Neurological Disorders and Stroke. Accessed May 1, 2026. <https://www.ninds.nih.gov/health-information/disorders/amyotrophic-lateral-sclerosis-als> 2. Mitchell JD, Borasio GD. Amyotrophic lateral sclerosis. *Lancet*. 2007;369(9578):2031-2041. 3. Cedarbaum JM, Stambler N, Malta E, et al; BDNF ALS Study Group (Phase III). The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. *J Neurol Sci*. 1999;169(1-2):13-21. 4. Amyotrophic lateral sclerosis (ALS). Mayo Clinic. Accessed May 1, 2026. <https://www.mayoclinic.org/diseases-conditions/amyotrophic-lateral-sclerosis/symptoms-causes/syc-20354022> 5. Atassi N, Berry J, Shui A, et al. The PRO-ACT database: design, initial analyses, and predictive features. *Neurology*. 2014;83(19):1719-1725. 6. Including the Multidisciplinary Team Approach in Your Care Plan. ALS.org. Accessed May 5, 2026. <https://www.als.org/sites/default/files/2020-04/Including-the-Multidisciplinary-Team-Approach-in-Your-Care.pdf> 7. Chatto C, Ryan L, Joyce NC. *Functioning When Mobility Is Affected by ALS*. Living with ALS Resource Guide 7. ALS.org. Revised 2022. Accessed May 1, 2026. <https://bit.ly/Resource-Guide-7> 8. ALS & caregiving. Les Turner ALS Foundation. Accessed May 1, 2026. <https://lesturnerals.org/caregiver/> 9. AARP and National Alliance for Caregiving. *Caregiving in the US 2025*. Washington, DC: AARP. July 24, 2025. Accessed May 1, 2026. doi:10.26419/ppi.00373.001 10. Kavanaugh MS, Cho CC, Howard M, et al. US data on children and youth caregivers in amyotrophic lateral sclerosis. *Neurology*. 2020;94(14):e1452-e1459. 11. ALS Insurance Navigator™. ALS Association. Accessed May 1, 2026. <https://www.als.org/support/als-insurance-navigator>

