



Start here. We're here for you.



Support • Resources • Information



ALS. It's the club you never thought you'd be a part of.

We're sorry you're here — but so glad you found us because we are here to help. This series is intended to help you figure out next steps and process the emotional rollercoaster that comes along with ALS.



Let's start with the basics.

What is ALS?

ALS is a neurodegenerative disease that causes progressive paralysis. What does this actually mean? ALS attacks cells in the body that control movement. It makes the brain stop talking to muscles leading to an inability to move, speak, swallow and breathe.

Limb-onset ALS occurs in your spinal cord and affects your arm, legs, hands, or feet. One of the first symptoms could be unexplained tripping or foot drop. (Foot drop is when you have trouble lifting the front part of your foot). This is the most common type of ALS.

Bulbar-onset ALS occurs in the bulbar area — your face, mouth, throat, or tongue. A telltale sign of bulbar-onset ALS is changes in speech or singing. This type of ALS is less common than limb-onset ALS.

Respiratory-onset ALS occurs in the respiratory muscles, and shortness of breath is typically an initial symptom associated with this form of ALS. This is a rare form of ALS onset.

People with ALS are typically told they will have 2-5 years to live. Learn more about the basics of ALS [here](#).

I or someone I love has ALS. What now?

We highly recommend getting a second opinion if you can. If you haven't already gotten one, use [this map](#) to find an ALS clinic near you.

Pro tip: If your insurance company gives you issues about covering a second opinion, **connect with an ALS Support Specialist** for resources on understanding your plan and how to advocate for coverage.

If you have a confirmed diagnosis of ALS, there are currently **two FDA-approved treatments** that may slow progression of symptoms. However, there are numerous clinical trials that are testing new therapies to treat ALS. We recommend using **ALS Signal: Clinical Research Dashboard**, which was created by people living with ALS and their caregivers, to find clinical trials that you may qualify for.

Pro tip: Start with **understanding the terms** used in ALS Signal to get the most out of it.

There is a lot to read and learn about, and sometimes you can't help but go down the Google rabbit hole at 2am. However, you can't trust everything you read or watch. Start with **this** list of questions and answers compiled by other people impacted by ALS. When you're ready for more, we've also pulled information from many trusted ALS organizations into one place so you can easily find vetted and trustworthy information. Find what you're looking for **here**.

For those who are U.S. Veterans

If the person living with ALS is a veteran, this likely qualifies them for 100% disability and compensation from the Veterans Association (VA), regardless of branch of service or what job they did while in the military, as long as you have 90 continuous days of active duty. Learn more about how to access benefits **here**.

LEARN MORE

This. Is. A. Lot.

Hearing that you or someone you love has ALS can feel like your world's axis has shifted. Whenever you feel overwhelmed, take a deep breath and then a few more. Allow yourself to feel your feelings -- scream, cry, go for a walk, or cuddle your pets. Take time to observe and process how you're feeling, but don't bottle it up. Consider **sharing this news** with at least one person you love and trust so they can start helping you. **Check out resources we've pulled together to help you lean on your community.**

MEET OUR I AM ALS SUPPORT SPECIALISTS

MCKENZIE MOK

ALS SUPPORT TEAM LEAD



ALLIE SEBESTA

ALS SUPPORT SPECIALIST



HOPE FEULING

ALS SUPPORT SPECIALIST



I AM ALS



Remember: You don't have to do this alone.

This community — the I AM ALS community — is now your community. One that will be there for you.

Want 1:1 support from someone who will listen and help you through the challenges of ALS?? Connect with an ALS Support Specialist who can help by sharing relevant medical and research information, supporting you emotionally, connecting you with practical resources and helping you build a community of support.

**CONNECT WITH AN ALS SUPPORT
SPECIALIST**



I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers and loved ones. It empowers advocates to raise mainstream awareness and lead the revolution against ALS in driving the development of cures. Learn more at iamals.org.

IAM ALS



1200 Pennsylvania Ave NW, #14135 | Washington, DC 20044
I AM ALS website