

Every ALS Journey Is Different

# Understanding Your Options Is the First Step Forward

Helpful Information for Those Newly Diagnosed with ALS

## Support for the Road Ahead

Receiving a diagnosis of ALS can be overwhelming. There's a lot to learn, many questions to ask, and important decisions you'll need to make along the way.

However, it's important to remember *you're not alone*. In addition to your network of friends and family, you can find medical, practical, and emotional support from healthcare provider(s), advocacy groups, and other people living with ALS.

This brochure was designed to help you better understand your diagnosis. Learning more about strategies to help manage ALS and working closely with your healthcare provider(s) can help you make the most informed decisions moving forward.

The information and advice provided here are general in nature and are not intended to be a substitute for professional medical advice, diagnosis, or treatment. You are strongly encouraged to seek the advice of your doctor or other qualified healthcare provider with any questions regarding a medical condition.



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**ALS** Pathways

# The Basics of ALS

The more you learn about your disease, the better prepared you may be for the path ahead.

## What Is ALS?<sup>1</sup>

Amyotrophic lateral sclerosis (ALS) is a progressive, disabling, fatal neurodegenerative disorder.

ALS begins in the brain and spinal cord by affecting nerve cells called **motor neurons**.

These motor neurons send commands from the brain to muscles throughout the body, allowing us to produce movements like walking, chewing, talking, and even breathing.

In people with ALS, these motor neurons stop working, cutting off this line of communication. Eventually, the brain loses its ability to control certain muscle movements, resulting in paralysis.

ALS is a progressive disease, meaning that symptoms get worse over time. People with ALS gradually lose their strength and muscle function, which can limit their ability to live an independent life.

## Did you know?

*In the US, ALS is also called Lou Gehrig's disease, named after the famous Yankees baseball player who was diagnosed with the disease in 1939.*

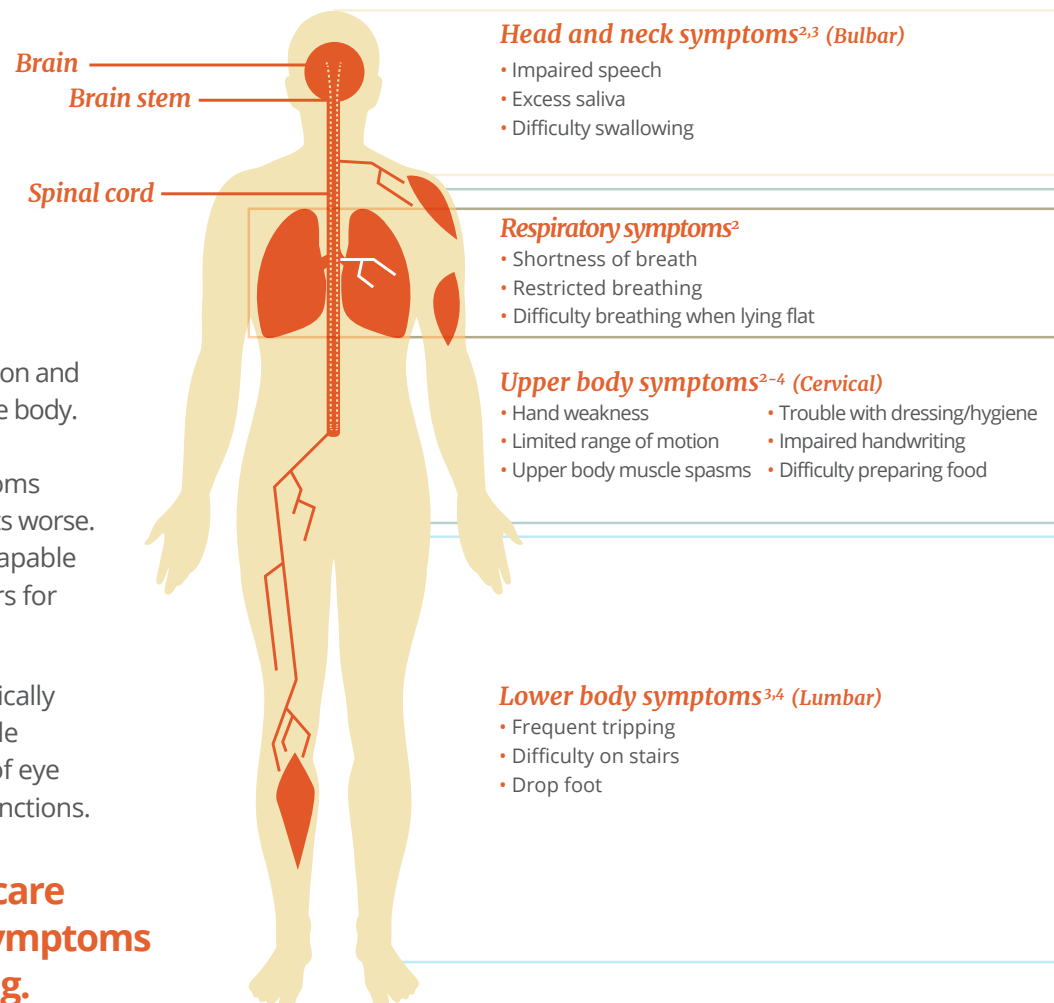
## Symptoms of ALS<sup>5,6</sup>

Symptoms vary from person to person and can appear in different regions of the body.

The number and degree of symptoms typically increase as the disease gets worse. Eventually, people may become incapable of movement and rely on caregivers for complete assistance.

However, most people's minds typically remain sharp and alert. Also, people with ALS usually maintain control of eye muscles and bladder and bowel functions.

**Speak with your healthcare provider(s) about any symptoms you may be experiencing.**



# Monitoring Your Disease

Tracking your disease progression will help you plan for what's to come.

## Tracking Disease Activity<sup>7</sup>

Several clinical tools that help monitor ALS symptoms have been developed, including questionnaires based on your function as well as tests that measure strength and breathing capacity. These tools are important to understand how ALS is affecting your body and how quickly it's progressing. Talk to your healthcare provider(s) about these tools.

## The ALSFRS-R Scale<sup>2,8,9</sup>

One of these tools is called the ALS Functional Rating Scale-Revised (ALSFRS-R). The ALSFRS-R is a questionnaire that measures changes in a person's physical function over time, from climbing stairs and using utensils to breathing and swallowing.

The ALSFRS-R is the most widely used test in clinical trials to track ALS and is considered the gold standard.

*The higher your score, the more function you have. The more slowly your score declines over time, the more slowly your disease is progressing.*

## Why Your Score Matters<sup>2,10</sup>

Your ALSFRS-R score can help you know how well your body is functioning. Understanding your physical function is important for two reasons:

### 1. Quality of Life

There is a strong connection between how well your body is functioning and quality of life. Generally, the better you're able to move, the more independence you'll retain.

### 2. Survival

The rate at which ALS worsens can be used to estimate survival time. Preserving physical function is believed to help patients live longer.

## Your Score Is Personal<sup>5</sup>

Remember, no two people with ALS are alike. Even if two people with ALS have the same overall score, ALS could still be affecting different regions of their bodies. For instance, take Steven and Mary, two hypothetical patients.



**Steven**  
**ALSFRS-R Score:** 42  
**Symptoms:** Difficulty writing and cutting food



**Mary**  
**ALSFRS-R Score:** 42  
**Symptoms:** Difficulty speaking and swallowing food

# Living with ALS

Receiving the right support may help you make the best decisions every step of the way.

## Communication Is Key

Because ALS affects every person differently, it's important to communicate regularly with your healthcare provider(s).

It's also important to maintain an open and honest dialogue with your caregivers, as well as to reach out to advocacy groups. They can help you manage your disease and provide emotional support.

## Explore Multidisciplinary Care<sup>11</sup>

In addition to working with your doctor or neurologist, you can find many experts under one roof at an ALS clinic.

ALS clinics provide multidisciplinary care, meaning many types of doctors and experts work together on your behalf to create a personalized care plan.

## Did you know?<sup>11,12</sup>

*Multidisciplinary care can help prolong survival time and help improve your mental and social well-being.*

## Learn about helpful interventions

As ALS gets worse, the muscles involved in vital body functions, such as eating and breathing, can weaken and make these tasks more challenging.<sup>13</sup>

Fortunately, certain interventions can assist with eating and breathing, which may enhance quality of life and help prolong survival.<sup>14,15</sup>

Discussing with your healthcare provider(s) the best time to start these interventions (and others like them) may help in the management of your disease.



### Proper Nutrition<sup>13</sup>

Malnutrition affects up to 50% of people with ALS.

Your healthcare provider(s) will consider a range of options, from consuming high-calorie food and liquids to using a percutaneous endoscopic gastrostomy (PEG) tube that is inserted directly into the stomach.



### Breathing Function<sup>1,13</sup>

As the muscles involved in respiration (breathing) weaken, it becomes harder to breathe. Respiratory failure is the leading cause of death in ALS, so it's important to intervene early.

Many patients begin receiving respiratory support through noninvasive ventilation (NIV), which delivers air to the lungs via face mask. As ALS progresses, more invasive options may be required, such as a tracheostomy, which is a surgically created opening in the trachea.

For More

Information

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



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## Tips for Managing ALS

You're not defined by ALS. These tips may help you cope with and manage your disease.



**Set personal goals:** Decide which goals and aspirations are most important to you, and stick to them. Concentrate on the things and people you love.



**Stay connected:** Surround yourself with family, friends and the things you love.



**Ask for help:** If you ever have a question or need help with a task, don't hesitate to ask your healthcare provider(s) and/or caregiver.



**Customize your home:** Consider modifying your home to be more accessible and easier to navigate.



**Plan your next steps:** Before leaving the house, always double check you have what you need to be prepared.



**Consider your emotional health:** A trained professional can help you and your loved ones cope with any emotions you're feeling.

## Treatment Options

Beyond interventions to assist with nutritional intake and breathing, there are different approaches that your healthcare provider(s) may prescribe or recommend to treat your disease.

**Your healthcare provider(s) may prescribe medications that:**

Can help with specific symptoms of your disease.

OR

Can help slow the progression of certain aspects of your disease.

Unfortunately, there is no cure for ALS, but you can work with your healthcare provider(s) to find a treatment option that may help you.

**Speak with your healthcare provider(s) about both types of treatment options.**

## Make Your Next Steps Count



**Plan Ahead:** Anticipate and address your future everyday needs. This can include prepping your home to make living with ALS easier.



**Find Your Care Team:** Seeking multidisciplinary care can help ensure that you have a comprehensive, personalized plan for treating ALS.



**Be Ready to Act:** Talk to your doctor about the steps you may need to take to deal with advanced ALS symptoms down the road. This way you'll know what to expect and when to take action.



**Take Advantage of Valuable Resources:** There are many helpful organizations that provide education, support services, patient advocacy, and research.

**Talk to your ALS healthcare provider(s) about patient service groups and programs available online and in your area.**



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