# ALS information to help you navigate the road ahead

## A helpful guide for those newly diagnosed with ALS

ALS Pathways™

Mitsubishi Tanabe Pharma Canada

# 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.

Remember that the more you know, the better equipped you will be to make informed decisions about your health. This brochure was designed to help you do just that – so that you better understand your diagnosis. With the knowledge of your healthcare team, you can also learn more about ALS and management strategies.

***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. Don't hesitate to reach out to your healthcare team for support and resources to help you moving forward.***

# Table of contents



**For more information about ALS, visit ALSPathways.ca**

# The basics of ALS

## What is ALS?

Amyotrophic lateral sclerosis (ALS) is a nervous system disease that affects physical function and may also include cognitive changes.

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

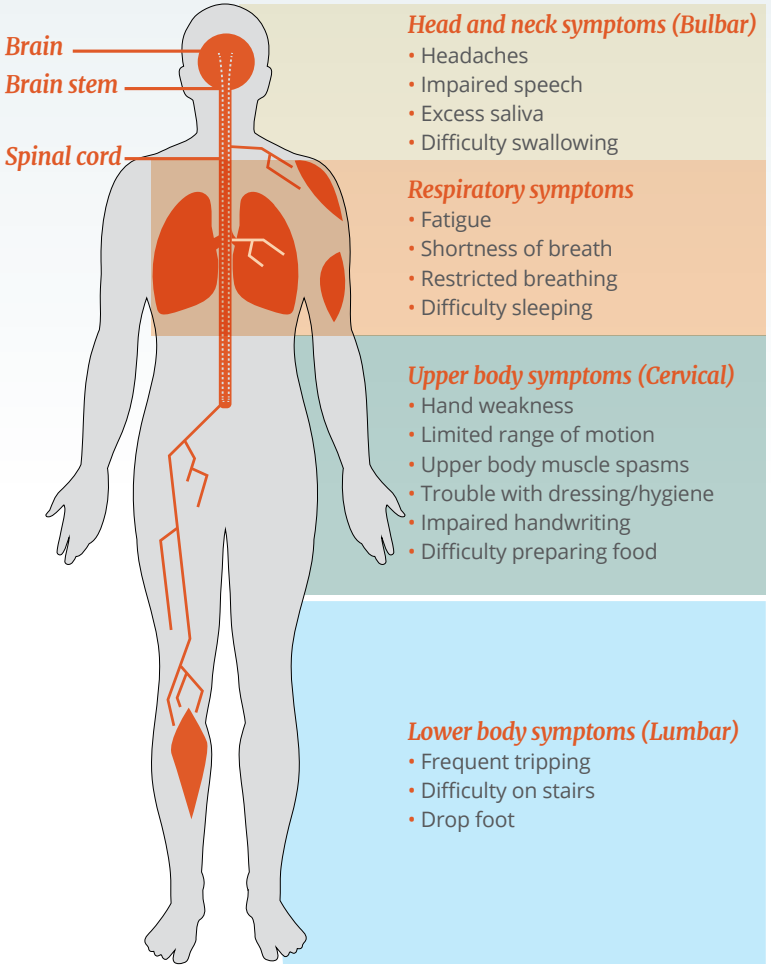
These motor neurons send commands from the brain to muscles throughout the body, allowing us to produce movements like walking, chewing, talking, and even breathing.

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 independent lives.

*Did you know?*

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




## Symptoms of ALS

Symptoms vary from person to person and often affect different regions of the body.

Over time, the number and degree of symptoms typically increase. At later stages of the disease, people may become incapable of movement and grow reliant on caregivers for complete assistance.

People with ALS usually maintain control of bladder and bowel functions. Additionally, their senses of sight, touch, hearing, taste, and smell typically remain unaffected.

### Cognitive and behavioural changes

A change in personality, conducting in inappropriate, embarrassing behaviour or in a childlike manner, making inappropriate comments, difficulty making decisions, impairments in thinking, reasoning or problem solving, and changes in language processing (such as improper use of grammar, difficulty spelling or speaking).

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

# Living with ALS

## 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.

Fortunately, there are interventions that can assist you with these tasks, which may enhance your quality of life and prolong survival.

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

### Proper nutrition

Keeping a healthy nutritional balance is important to enhancing your strength and energy.

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

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). As ALS progresses, more invasive options may be required, such as a tracheostomy, which is a surgically created opening in the trachea.

## Monitoring function

Frequently monitoring decline in function is important for understanding how ALS affects your body. The most widely used test in clinical trials to track ALS is called the **ALS Functional Rating Scale-Revised (ALSFRS-R)**.

The ALSFRS-R is a questionnaire you can get from your healthcare provider to track changes in physical function over time, from climbing stairs and using utensils to breathing and swallowing.

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

Talk to your healthcare provider(s) about any changes to your ALSFRS-R scores.

## Why your ALSFRS-R score matters

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

No two people with ALS are alike, meaning every ALSFRS-R score is completely personal and unique. 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.*

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

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

*Steven and Mary are hypothetical people with ALS.

## Communication is key

Because ALS affects every person differently, it's important to communicate regularly with your healthcare provider(s). They can help monitor your disease progression, manage any symptoms you may be experiencing, and connect you with information and resources you may need.

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

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

Many ALS clinics provide multidisciplinary care, meaning you can find healthcare providers with different specialties working together to create a personalized care plan for you. Your team may consist of neurologists, nurse coordinators, physiotherapists, speech language pathologists, occupational therapists, respiratory therapists, social workers, dietitians, and research coordinators.

*Did you know?*

**Multidisciplinary care can help provide benefits including, prolonged survival time, fewer and shorter hospital admissions compared to those who do not receive multidisciplinary care, and increased use of adaptive equipment.**

*For more information, visit ALSPathways.ca*

## 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 people and 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.

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

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

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

**Explore assistive devices:** There are many types of equipment that can help you maintain your independence for longer and be more comfortable.

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

## Make your next steps count

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

**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.

**Find your care team:** Seeking multidisciplinary care may help ensure that you have a comprehensive, personalized plan for treating ALS.

**Take advantage of valuable resources:** There are many helpful organizations that provide education, support services, patient advocacy, and research.

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

## Take notes

As you speak with your healthcare provider(s), use the space below to take note of any additional tips or best practices they recommend. If you have difficulty writing, ask a caregiver or loved one to take notes for you.

**For more information on ALS, as well as tools and resources for caregivers, visit ALSPathways.ca**

Mitsubishi Tanabe Pharma Canada