



ALS QUICK FACTS

ALS STANDS FOR

AMYOTROPHIC LATERAL SCLEROSIS



ALS is a **terminal, progressive, neurodegenerative disease**. It is **not contagious**. Anyone can develop ALS at any time regardless of gender, socioeconomic status, geography, or race – although it most often affects people between ages 40 and 60.

The motor neurons that communicate messages from the brain to the muscles of the body that we use to move, talk, eat, swallow, and breathe break down and die in people who have ALS. This means the brain communicates less and less with these muscles, causing them to weaken and eventually stop working.

ALS is also known as **Lou Gehrig's disease** or **motor neuron disease (MND)**.

ALS BY THE NUMBERS

Nearly

4,000

Canadians are currently living with ALS

2 to 3

people are diagnosed with ALS every day in Canada

1 in 300

is the lifetime risk for anyone to develop ALS

80%

of people with ALS die within 2 to 5 years of diagnosis

1,000

Canadians die from ALS and a similar number are diagnosed with ALS every year

30%

of ALS diagnoses are bulbar ALS where muscles of the head, face, and neck become paralyzed before the rest of the body

90%+

of people diagnosed with ALS do not have a family history of the disease

15 to 25%

of ALS cases have a known genetic mutation even without a family history of the disease

SIGNS AND SYMPTOMS

Symptoms are a result of weakening muscles and can vary from person to person. Some common signs and symptoms include:

- Tripping
- Dropping things
- Slurred speech
- Difficulty swallowing
- Shortness of breath
- Weight loss
- Fatigue
- Weakness
- Muscles cramping or twitching

Some individuals experience non-motor symptoms including, but not limited to cognitive and behavioural changes, gastrointestinal issues, pain, and sleep disturbances. The type and severity of these changes varies from individual to individual.

DIAGNOSIS

A neurologist may use these tests to help diagnose ALS through the process of elimination:



Blood and urine studies



Electrodiagnostic tests



Magnetic resonance imaging (MRI)



Muscle and nerve function tests

TREATMENT

There is no cure for ALS. However, there are three Health Canada approved treatments that may help to slow progression of ALS:

- **Rilutek (riluzole)**
- **Radicava (edaravone)**
- **Qalsody (tofersen)**
(for the treatment of SOD1-ALS)

SUPPORT

ALS can be an incredibly challenging disease – physically, emotionally, psychologically, and financially. There is support available for Canadians living with ALS and their families through the ALS Society of Canada (ALS Canada) and the provincial ALS Societies. ALS Canada provides services and programs in these four areas:

Research

Investing in the most impactful fundamental and clinical research that will fuel scientific discovery leading to life-changing treatment and maintaining a strong partnership with the network of clinicians across Canada dedicated to ALS research and clinical care.

Community Services

Directly supporting people affected by ALS to ease their journey – through a hybrid model of in-home and virtual interactions, facilitated support groups, and provision of mobility equipment and communication devices in Ontario and clinical care.

Advocacy

Advocating for policy changes that will have a meaningful impact on people living with ALS including equitable, timely, and affordable access to therapies, improved home and community care, and research funding.

Education

Providing resources and learning opportunities on a variety of topics concerning the ALS community, including webinars, fact sheets, and the Canadian ALS Learning Institute to empower informed decision-making.

Across Canada, provincial ALS Societies provide local support to people living with ALS and their families, with ALS Canada providing community-based services to Ontario residents. Contact your provincial ALS Society to learn more. Please note: ALS Canada provides oversight and support for Nunavut as needed.

ALS Society of Canada (and Ontario)

180 Bloor St W #500, Toronto, ON M5S 2V6
416-497-2267 | als.ca

ALS Society of British Columbia (and Yukon)

12328 - 13351 Commerce Parkway, Richmond, BC V6V 2X7
1-800-708-3228 | alsbc.ca

ALS Society of New Brunswick and Nova Scotia

1000 Windmill Rd, Dartmouth, NS B3B 1B4
902-454-3636 | alsnbns.ca

ALS Society of Newfoundland & Labrador

3 Herald Ave, Suite 3, Corner Brook, NL A2H 4B8
1-888-364-9499 | alsnl.ca

ALS Society of Saskatchewan

2430 8th Ave, Unit C, Regina, SK S4R 5E3
306-949-4100 | alssask.ca

ALS Society of Alberta (and Northwest Territories)

7874 10 Street NE, Calgary, AB T2E 8W1
403-228-3857 | alsab.ca

ALS Society of Manitoba

2A-1717 Dublin Ave, Winnipeg, MB R3H 0H2
204-831-1510 | alsmb.ca

ALS Society of Prince Edward Island

P.O. Box 1643, Summerside, PEI C1N 2V5
902-439-1600 | alspei.ca

ALS Society of Québec

5415 Paré Street, Suite 200 Mount-Royal, QC H4P 1P7
514-725-2653 | sla-quebec.ca