



# Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's disease, is a progressive neurological disease that affects roughly 30,000 people in the United States; about 5,000 new cases are diagnosed each year.



## Q: What is ALS?

ALS belongs to a class of disorders known as motor neuron diseases. Motor neurons are nerve cells located in the brain, brainstem, and spinal cord that serve as controlling units and vital communication links between the nervous system and the voluntary muscles of the body. The loss of these cells causes the muscles under their control to weaken and waste away, leading to paralysis. The symptoms of ALS worsen with time. It is usually fatal within five years of diagnosis, but about 10% of patients live for a decade more.

### **Q: What causes ALS?**

The cause of ALS is unknown. Scientists are currently investigating genetic and environmental factors.

Most cases of ALS are considered sporadic, with the disease seeming to occur at random. About 10 percent of cases are familial, with links to defects or mutations in certain genes. Individuals whose family members have ALS are at higher risk, but overall the risk is very low, and most will not develop the disease.

ALS can occur at any time, but typically strikes in mid-life, with most individuals diagnosed between the ages of 55 and 75. Men are about one-and-a-half times more likely to have the disease as women.

### **Q: What are the symptoms of ALS?**

ALS manifests itself in different ways, depending on which muscles weaken first. Symptoms may include tripping and falling, loss of control in hands and arms, difficulty speaking, swallowing and/or breathing, persistent fatigue, and twitching and cramping.

Because ALS affects only motor neurons, the disease does not usually impair a person's mind, personality, intelligence, or memory. It does not affect a person's ability to see, smell, taste, hear, or recognize touch. Individuals with ALS usually maintain control of bladder and bowel function but may experience increased urine urgency (the pressing sensation of needing to urinate) and constipation.

### **Q: How is ALS treated?**

There is no cure for ALS, nor is there a proven therapy that will prevent or reverse its course. The Food and Drug Administration (FDA) has approved the use of riluzole to manage ALS. The drug has been shown to prolong the life of ALS patients by several months, mainly in those with difficulty swallowing, and extend the time before a person needs ventilation support. Riluzole does not reverse the damage already done to motor neurons, and patients taking the drug should be monitored for liver damage and other possible side effects.

### **Q: What can I do to maintain my physical health with ALS?**

Physical therapy and special equipment can enhance independence and safety throughout the course of ALS. Low-impact aerobic exercise such as walking, swimming, and stationary bicycling can strengthen unaffected muscles, improve cardiovascular health, and help patients fight fatigue and depression. Range of motion and stretching exercises can help prevent painful spasticity and muscle contractures. Occupational therapists can suggest devices such as ramps, braces, walkers, and wheelchairs that help patients conserve energy and remain mobile.

### **Q: What other supports might help me navigate this diagnosis?**

Social workers and home care and hospice nurses help patients, families, and caregivers with the medical, emotional, and financial challenges of living with ALS, particularly during the final stages of the disease. Social workers provide support such as assistance in obtaining financial aid, arranging durable power of attorney, preparing a living will, and finding support groups for patients and caregivers.

### **Q: Are there clinical trials for ALS?**

Yes. To find current ALS trials, visit ClinicalTrials.gov (<https://www.clinicaltrials.gov>), a searchable website for publicly and privately supported clinical studies maintained by the National Library of Medicine at the National Institutes of Health\_ (<https://www.nih.gov>).

*Sources: National Institute on Neurological Disorders and Stroke, ALS Association, Merck Manual, Centers for Disease Control and Prevention.*

#### **Need to talk to someone?**

Our Information Specialists are available to answer your questions.

Call toll-free 1-800-539-7309 Mon-Fri, 9 am-8 pm EST.

Or schedule a call or ask a question online at

<https://www.ChristopherReeve.org/Ask>.

## **Resources for ALS**

### **ALS Association (ALS)**

<http://www.als.org>

1300 Wilson Blvd. Suite 600

Arlington, VA 22209

Phone: 800-782-4747 (Toll-free for information and referrals to care services.)

Email: [alsinfo@als.org](mailto:alsinfo@als.org)

ALS is a national non-profit organization dedicated to finding a cure for amyotrophic lateral sclerosis and supporting individuals living with the disease. This site provides

news, research updates, and information about local support groups. Please see Living with ALS Resource Guides, available for free download. <https://www.als.org/navigating-als/resources/living-als-resource-guides>

### **ALS Patient Care Database (ALS C.A.R.E)**

<https://www.outcomes-umassmed.org/ALS/>

Conducted between 1996 and 2005, this was the first large-scale effort to track the disease course and outcomes of patients with ALS. The project enrolled over 6,000 patients from more than 300 clinical sites in the USA. Long-term follow-up was conducted through clinical assessment, patient self-reported questionnaires, and caregiver assessment.

### **ALS Hope Foundation**

<http://www.alshopefoundation.org/>

1333 Race Street, Suite 202

P.O. Box 40777

Philadelphia, PA 19107

Phone: 215-568-2426

Email: [info@ALSHopeFoundation.org](mailto:info@ALSHopeFoundation.org)

The ALS Hope Foundation works to advance a cure for ALS, support clinical centers of excellence, and increase education and awareness about the diagnosis, treatment, and care of those living with the disease.

### **ALS Recovery Fund**

[www.alsrecovery.org](http://www.alsrecovery.org)

One Grove Isle Drive #1602

Coconut Grove, FL 33133

Phone: 305-971-5416

Email: [info@alsrecovery.org](mailto:info@alsrecovery.org)

The ALS Recovery Fund is a non-profit organization that provides financial assistance to help families living in Miami-Dade, Broward, Monroe, and Palm Beach Counties obtain equipment and supplies for loved ones living with ALS.

### **ALS Society of Canada**

<https://www.als.ca/>

393 University Ave, Suite 1701

Toronto, ON M5G 1E6

Phone: 905-248-2052, 800-267-4257 (Toll-free)

Email: [communityservices@als.ca](mailto:communityservices@als.ca)

The ALS Society works to fund research toward treatments, support individuals living with ALS, and promote increased public awareness about the disease.

### **ALS Society of Canada: A Manual for People Living with ALS**

<https://als.ca/wp-content/uploads/2020/03/ALS-guide-ON-EN-WEB.pdf>

This guide is an educational resource and tool designed to help families and individuals manage ALS care. Topics include signs, symptoms, and research; tips and tools for patients and family caregivers; mobility and independence; swallowing and nutrition; speech and communication; breathing and lung function; end-of-life issues and advance-care planning; assistive equipment and activities of daily living; legal and financial considerations; and education and support resources.

### **ALS Therapy Development Institute (ALS TDI)**

<http://www.als.net/>

480 Arsenal St., Suite 201

Watertown, MA 02472

Phone: 617-441-7200

Email: [info@als.net](mailto:info@als.net)

ALS TDI is a non-profit biotechnology organization dedicated to developing effective treatments for ALS.

### **ALS Worldwide**

<http://www.alsworldwide.org>

1800 North Prospect Ave., Suite 4B

Milwaukee WI 53202

Phone: 414-831-6879

Email: [info@alsworldwide.org](mailto:info@alsworldwide.org)

ALS Worldwide is a non-profit organization that provides information and support to ALS patients and their families. Resources include current research updates, podcasts, and articles about medical devices, nutritional supplements, and self-help strategies.

### **Angel Fund**

<http://www.theangelfund.org/>

649 Main Street

Wakefield, MA 01880

Phone: 781-245-7070

Email: [theangelfunds@gmail.com](mailto:theangelfunds@gmail.com)

The Angel Fund is a non-profit organization that supports ALS research at the UMASS Chan Medical School by raising funds through events, campaigns, foundation grants and community outreach activities.

### **Brigance Brigade Foundation**

<http://www.brigancebrigade.org/>

10045 Red Run Blvd., Suite 130

Owens Mills, MD 21117

Phone: 410-878-2030

Email: [info@brigancebrigade.org](mailto:info@brigancebrigade.org)

This organization, founded by former NFL player OJ Brigance after he was diagnosed with ALS, provides grants, equipment and support services to people living with the disease.

### **Hope Loves Company**

<http://www.hopelovescompany.org/>

210 Park Ave., Suite 324

Worcester, MA 01609

Phone: 609-730-1144

Email: [Contact-Us@hopelovescompany.org](mailto:Contact-Us@hopelovescompany.org)

HLC is a non-profit organization providing educational services and emotional support to children and young adults whose loved ones have or had ALS or Lou Gehrig's Disease. Its programs include a free overnight camp and virtual support group.

### **International Alliance of ALS/MND Associations**

<http://www.alsmndalliance.org>

E-mail: [alliance@als-mnd.org](mailto:alliance@als-mnd.org)

The International Alliance provides a forum for support and the exchange of information between worldwide ALS or Motor Neurone Disease (MND) associations. Its resources include webinars on topics including mental health, clinical trials, and maintaining independence, and an annual ALS educational conference for healthcare professionals.

### **Les Turner ALS Foundation**

<http://www.lesturnerals.org>

5550 W Touhy Avenue, Suite 302

Skokie, IL 60077-3254

Phone: 847-679-3311

Email: [info@lesturnerals.org](mailto:info@lesturnerals.org)

The Les Turner ALS Foundation works to advance research, patient care, and education about ALS and other motor neuron diseases. It supports ALS research at Northwestern University and provides grants for families in need of assistive technology, respite, and transportation to treatment appointments at Northwestern.

### **Muscular Dystrophy Association – ALS Division**

<http://mda.org/disease/amyotrophic-lateral-sclerosis>

Muscular Dystrophy Association

161 N. Clark, Suite 3550

Chicago, IL 60601

Phone: 800-572-1717

Email: [mda@mdausa.org](mailto:mda@mdausa.org)

MDA offers a range of services to people with ALS and supports a worldwide research program. The site contains ALS-related publications and educational materials.

### **National ALS Registry**

<http://www.cdc.gov/als>

Phone: 800-232-4636 TTY: 888-232-6348

The CDC hosts the National ALS Registry. The goal of the registry is to collect information to help scientists learn more about ALS.

### **National Institute of Neurological Diseases and Stroke (NINDS): ALS Fact Sheet**

<https://www.ninds.nih.gov/disorders/patient-caregiver-education/fact->

[sheets/amyotrophic-lateral-sclerosis-als-fact-sheet](#)**NINDS**

P.O Box 5801

Bethesda, MD 20824

Phone: 800-352-9424

NINDS is part of the National Institutes of Health. This page has information on ALS, including treatment, prognosis, research, and links to other organizations and publications.

**NINDS: Amyotrophic Lateral Sclerosis (ALS) booklet**

<https://catalog.ninds.nih.gov/publications/amyotrophic-lateral-sclerosis>

Click on Download Digital Version.

This booklet provides an overview of amyotrophic lateral sclerosis, including common symptoms, diagnosis, and available therapies.

**Northeast ALS Consortium (NEALS)**

<https://www.neals.org/>

200 Portland St., 5th Floor

Boston, MA 02114

Phone: 877-458-0631 (Toll-free)

Email: [alstrials@neals.org](mailto:alstrials@neals.org)

NEALS works to support clinical research and new treatments for people with ALS and motor neuron disease. Its website features webinars on ALS research for families and caregivers and a clinical trial database.

**Team Gleason**

<http://www.teamgleason.org/>

The Gleason Initiative Foundation

PO Box 24493

New Orleans, LA 70184

Phone: 504-934-1037

Team Gleason is a non-profit organization that provides assistive technology, equipment, and care services to individuals with neuromuscular diseases or injuries; adventure trips for individuals with ALS are also funded and documented to raise awareness about the disease. Steve Gleason is a former NFL player who founded the organization when he developed ALS.

**Internet Forums****ALS Forum**

<http://www.als.net/forum/>

This forum (managed by the ALS Therapy Development Institute) lets community members exchange information about ALS, including daily living tips, research, and treatments. Forum members include people living with ALS, caregivers, family members, friends, neurologists, neurodegenerative disease researchers, and pharmaceutical executives.

**ALSforums**

<http://www.alsforums.com>

The ALS support forum is an open support community for individuals directly or indirectly affected by ALS and MND.

**Patients Like Me: ALS**

<http://www.patientslikeme.com/conditions/9-amyotrophic-lateral-sclerosis>

Patients Like Me features community forums for medical conditions and diseases including ALS.

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