Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS), also called Lou Gehrig’s disease, is a progressive neurological disease affecting 30,000 Americans with about 5,000 new cases occurring in the United States each year.

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. It is usually fatal within five years of diagnosis.

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. ALS strikes in mid-life. Men are about one-and-a-half times more likely to have the disease as women. People with ALS may want to look into speech-generating devices which allow them to “voice bank” their voice as they lose the ability to speak. Voice banking allows an individual to record and store commonly used words or family names spoken in their own voice that can be replayed later.

Because ALS affects only motor neurons, the disease does not 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. Patients usually maintain control of eye muscles and bladder and bowel functions.

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) recently approved riluzole, the first drug that has been shown to prolong the survival of ALS patients. Riluzole is believed to reduce damage to motor neurons by decreasing the release of glutamate. Clinical trials showed that Riluzole prolongs survival by
several months, mainly in those with difficulty swallowing. The drug also extends the time before a person needs ventilation support. Riluzole does not reverse the damage already done to motor neurons, and patients taking the drug must be monitored for liver damage and other possible side effects.

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.

When the muscles that assist in breathing weaken, use of ventilatory assistance (intermittent positive pressure ventilation [IPPV] or bilevel positive airway pressure [BIPAP]) may be used to aid breathing during sleep. When muscles are no longer able to maintain oxygen and carbon dioxide levels, these devices may be used full-time.

Social workers and home care and hospice nurses help patients, families, and caregivers with the medical, emotional, and financial challenges of coping 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.

Sources:

National Institute on Neurological Disorders and Stroke, National ALS Association, Christopher & Dana Reeve Foundation website.

Web Sites

**ALS Association (ALSA)**

http://www.alsa.org

1300 Wilson Blvd. Suite 600

Arlington, VA 22209

Care services (providing information and referrals): 800-782-4747 (Toll-free)

E-mail: alsainfo@alsa-national.org

ALSA is a national not-for-profit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis. This site is rich with news, research support, resources and connections. They publish a 6-volume set of books free to those with ALS called *Living with ALS* (What’s It All About, Coping with ALS, Managing Your Symptoms, Functioning When Your Mobility is Affected, Adjusting to Swallowing and Speaking Difficulties, Adapting to Breathing Changes).
The ALS Patient Care Database (ALS C.A.R.E)
https://www.outcomes.umassmed.org/ALS/

(1996-2005) was the first large-scale effort to track the disease course and outcomes of patients with amyotrophic lateral sclerosis. The project enrolled over 6000 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 is supported by a grant from Sanofi and managed by the Center for Outcomes Research, University of Massachusetts Medical School (http://www.umassmed.edu/).

ALS Family Charitable Foundation
http://alsfamily.org/
One Trowbridge Rd., Suite 322
 Bourne, MA 02532
 Phone: 508-759-9696
 Email: ALSFamily@aol.com

The ALS Family Charitable Foundation is dedicated to raising funds to provide patient services for those living with ALS and to support cutting edge research to cure ALS in the future. They help ALS patients and their families with in-house grants. Their services are open to New England area families and include support for respite, college scholarships, summer camp, back to school shopping, utility bills, vacations and so much more.

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

The mission of the ALS Hope Foundation is to provide long-term support to 1) basic and clinical research programs leading to a cure, 2) clinical centers of excellence for the care and treatment of patients with ALS, 3) support programs for patients and caregivers that optimize care and promote independence of the patient, and 4) programs that promote patient and physician education about the diagnosis, treatment and caring for the patient with ALS. The Foundation funds clinical research and education at the MDA/ALS Center of Hope and the Neuromuscular Research Laboratory at Drexel University College of Medicine.

ALS Recovery Fund
www.alsrecovery.org
One Grove Isle Drive #1602
Coconut Grove, FL 33133
Phone: 305-971-5416

The ALS Recovery Fund is a 501(c)(3) non-profit charitable organization that is committed to creating public awareness, promoting research and education, and
raising funds for patient care and research in order to find a cure for this life threatening disease.

**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)
The ALS Society is committed to: supporting research towards a cure for ALS, supporting provincial ALS societies in their provision of quality care for persons living with ALS, and building public awareness of ALS and its impact.

**ALS Society of Canada: A Manual for People Living with ALS**
The sixth edition of the Manual for People Living with ALS Manual is an educational resource and tool that helps readers to organize personal health information and stimulate discussion between patients, family members, and their health-care providers about managing ALS care and coping with an often rapidly progressive neurological condition. The manual covers: ALS, signs, symptoms, and research; tips and tools for patients and family caregivers; where to go for help and support; disease management information about who makes up the ALS health-care team, mobility and independence, swallowing and nutrition, speech and communication, breathing and lung function, oral care, end-of-life issues, and advance-care planning; assistive equipment and activities of daily living; legal and financial considerations; and education and support resources. The manual can be searched and read online. Physical copies are free when ordered by people living with ALS, their caregivers, or their healthcare providers.

**ALS Therapy Development Institute (ALS TDI)**
http://www.als.net/
480 Arsenal St., Suite 201
Watertown, MA 02472
Phone: 617-441-7200
E-mail: info@als.net
ALS TDI is a nonprofit biotechnology organization dedicated to developing effective treatments for ALS.

**ALS Worldwide**
http://www.alsworldwide.org
Stephen and Barbara Byer, Co-Executive Directors
1800 North Prospect Ave., Suite 4B
Milwaukee WI 53202
Phone: 414-831-6879
ALS Worldwide is a non-profit organization for ALS patients and their families to obtain information, advice, direction, support, guidance and hope. Support for
both patients and family members is available through individual telephone and email contact.

**The Angel Fund**
649 Main Street
Wakefield, MA 01880
Phone: 781-245-7070
A non-profit organization whose mission is to support research and scientific investigations at the Cecil B. Day Laboratory by raising funds through events, campaigns, foundation grants and numerous other community outreach activities, to aid in finding a cause, treatment and cure for ALS.

**Brigance Brigade Foundation**
10045 Red Run Blvd., Suite 130
Owens Mills, MD 21117
Phone: 410-878-2030
OJ Brigance, a former NFL player, founded this non-profit organization after his diagnosis with ALS to equip, empower and encourage people living with ALS.

**Hope Loves Company**
65 Main St., Suite 101
Pennington, NJ 08534
Phone: 609-730-1144
Email: [Contact-Us@hopelovescompany.org](mailto:Contact-Us@hopelovescompany.org)
HLC is the only non-profit organization in the U.S. dedicated to providing educational or emotional support to children and young adults whose loved ones have or had ALS or Lou Gehrig’s Disease.

**International Alliance of ALS/MND Associations**
[http://www.alsmndalliance.org](http://www.alsmndalliance.org)
E-mail: [alliance@als-mnd.org](mailto:alliance@als-mnd.org)
The International Alliance was founded in November 1992 to provide a forum for support and the exchange of information between worldwide ALS or Motor Neurone Disease (MND) associations. It now numbers more than 50 national patient support and advocacy groups from over 40 countries worldwide.

**Les Turner ALS Foundation**
[http://www.lesturnerals.org](http://www.lesturnerals.org)
5550 W Touhy Avenue, Suite 302
Skokie, IL, 60077-3254
Phone: 847-679-3311
E-mail: [info@lesturnerals.org](mailto:info@lesturnerals.org)
The Les Turner ALS Foundation is a leader in research, patient care, and education about ALS and other motor neuron diseases. The Foundation serves
more than 90% of the ALS population in the Chicago area and reaches the ALS community worldwide through wide-ranging research and symposiums for health care professionals.

**Momma Mary Foundation**
https://www.facebook.com/MommaMaryFoundation/
PO Box 826
631 Grove St.
Jersey City, NJ 07310
Mary Valastro, mother of Buddy Valastro of Cake Boss TV fame, was diagnosed with ALS and the family started a non-profit organization in her name. Mary passed away in June 2017.

**Muscular Dystrophy Association – ALS Division**
http://mda.org/disease/amyotrophic-lateral-sclerosis
Muscular Dystrophy Association – USA
National Headquarters
161 N. Clark, Suite 3550
Chicago, IL 60601
Phone: 800-572-1717
E-mail: mda@mdausa.org
MDA offers a comprehensive range of services to people with ALS and has a worldwide research program. The site has ALS-related publications.

**National ALS Registry**
http://www.cdc.gov/als
Phone: 800-232-4636 TTY: 888-232-6348
The CDC hosts the National ALS Registry which started in Fall 2010. 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**
This page has information on ALS, including treatment, prognosis, research, and links to other organizations and publications.

**NINDS: Amyotrophic Lateral Sclerosis (ALS) booklet**
Click on Download Digital Version

**Northeast ALS Consortium (NEALS)**
https://www.neals.org/
200 Portland St., 5th Floor
Boston, MA 02114
Phone: 877-458-0631 (Toll-free)
E-mail: alstrials@neals.org

NEALS' mission is to rapidly translate scientific advances into clinical research and new treatments for people with ALS and motor neuron disease. NEALS offers live, online seminars (webinars) on ALS research for people with ALS and other motor neuron disease. The site provides a clinical trial database and allows people to find an ALS specialist.

Team Gleason  
http://www.teamgleason.org/  
The Gleason Initiative Foundation  
PO Box 24493  
New Orleans, LA 70184  
Phone: 504-934-1037  
Email: 37@teamgleason.org  
Team Gleason is a non-profit organization whose mission is to help provide individuals with neuromuscular diseases or injuries with leading edge technology, equipment and services. Additionally they work to raise public awareness toward ALS by providing and documenting extraordinary life adventures for individuals with muscular diseases or injuries. Steve Gleason is a former NFL player who founded the organization when he developed ALS.

CD-ROM

A privately collected compilation of U.S. government documents on ALS from sources like NIH, CDC, etc.

Internet Forums

ALS Forum  
http://www.als.net/forum/  
The purpose of this forum (managed by the ALS Therapy Development Institute) is to exchange information about ALS, scientific advances, and treatments. Forum members include people living with ALS today as well as their caregivers, family members, friends, neurologists as well as 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 has discussion forums. Founded by Ben and Jamie Heywood after their brother was diagnosed with ALS.
The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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