



Understanding Amyotrophic Lateral Sclerosis



Douglas, diagnosed in 2006,
with his wife, Jackie.



What Is Amyotrophic Lateral Sclerosis?

Amyotrophic lateral sclerosis (ALS) is a progressive degenerative disorder of the nervous system. It is also known as Lou Gehrig's disease.

ALS attacks motor neurons, which are nerve cells in the brain and spinal cord. These cells send messages to muscles throughout the body. In ALS, the motor neurons die. The ability of the brain to start and control muscle movement is lost. As a result, muscles gradually weaken. In time, most muscles are affected, including those that control swallowing and breathing. For most people, weakness tends to progress, causing death in three to five years. About 10 percent of people with ALS live for 10 years or longer with the disease.

While ALS can develop at any age, it generally occurs between the ages of 40 and 70. About 5,000 people in the United States are diagnosed with ALS each year.

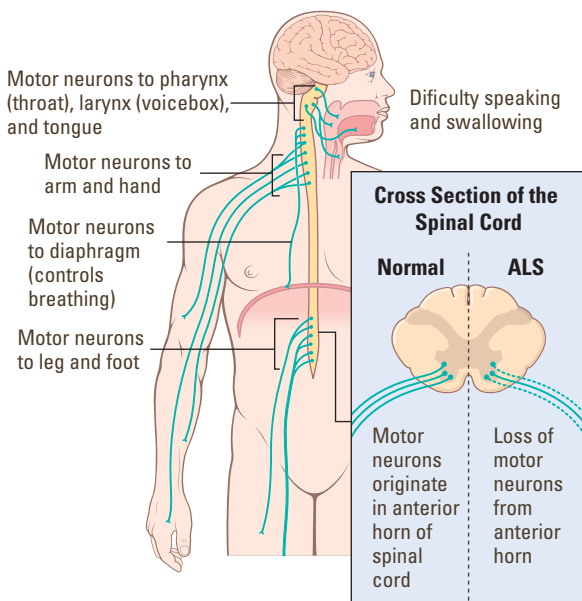
What Are the Symptoms?

ALS usually comes on slowly. The first signs are often arm or leg weakness, problems with speaking or swallowing, muscle twitches or cramps, loss of muscle bulk, or stiff muscles. Some people laugh or cry more easily. In time, all muscles involved with voluntary movement can be affected. ALS does not affect involuntary muscles, such as those that control the heart and the digestive system.

Did you know?

Neurologists are medical doctors who specialize in disorders of the brain and nerves. They are the specialists who most often diagnose and treat people with ALS.

Motor Neurons and ALS



How Is ALS Diagnosed?

ALS is a difficult disease to diagnose. There is no single test to diagnose ALS. The diagnosis is based on the symptoms and signs of the disease and a series of tests to rule out other diseases. A test of nerves and muscles called electromyography and nerve conduction studies (EMG/NCS) may help confirm the diagnosis. Many disorders, such as cervical spine disease and conditions that affect the peripheral nerves, can mimic ALS. Seeing a neurologist with experience in diagnosing ALS is important. If there is uncertainty, seeking a second opinion is sometimes helpful.

What Causes ALS?

Two types of ALS occur. Most people have sporadic, or random, ALS, in which the cause is not known. The children of people with sporadic ALS are at no greater risk of developing the disorder than other people. Five percent to 10 percent of those with ALS have familial ALS. They have a family history of the disorder and show a dominant genetic pattern. In this form, offspring have about a 50-percent chance of inheriting the gene mutation, putting them at risk of developing the disease.

What Are the Treatments?

There is no known cure for ALS, but research is promising. The drug riluzole modestly increases survival time. Much can be done to make life easier and longer for people with ALS. The goal of treatment is to maintain function and independence for as long as possible.

Therapies are available that can be helpful in treating some symptoms of ALS. Research shows that using an assisted-breathing device may increase life expectancy and slow down development of breathing problems. Research also shows that using a feeding tube may help stabilize body weight and prolong survival. Treatments are also available for excess saliva and drooling due to swallowing problems.

People with ALS need to take an active role in planning and carrying out their treatment. A neurologist is the doctor best qualified to lead the treatment team. Ideally, physical, occupational, speech, respiratory, and nutrition therapists will also be involved. Research has shown that people who are treated at a specialized, multidisciplinary ALS clinic may live longer and have a better quality of life.

Living with ALS

Medications and assistive devices can help manage the symptoms of ALS. Talk to your doctor about your concerns. Treatments are available for many symptoms.

ALS support groups can be a source of help, comfort, and information. You can learn how other people with ALS are managing the physical and emotional changes that are part of the disorder. You can also learn about new ways of managing your symptoms and current research.

Partnering with Your Neurologist

To provide the best care, your neurologist needs to know all about your symptoms and medical history. Likewise, you need to get answers to your questions. Keeping a notebook about your condition and bringing a few well-organized questions to your appointments can be helpful.

For Family and Friends

Caring for a loved one with ALS can be both physically and emotionally exhausting. If you are caring for a family member or friend with ALS, take care of yourself, as well. Avoid the feeling that you have to do it all yourself. Get help from family, friends, and professionals. Many support groups are available for caregivers. See **Resources** for organizations to contact.

Help Us Cure Brain Disease

Make a Donation to Research

The American Brain Foundation supports vital research and education to discover causes, improved treatments, and cures for brain and other nervous system diseases. To learn more or to make a donation to support research, visit www.CureBrainDisease.org.

Make Your Voice Heard

To keep research advancing toward future cures and treatments for brain disease, it is important for people affected by neurologic disorders to advocate for more research funding. Contact your members of Congress and ask them to support neurology research by increasing funding for the National Institutes of Health (NIH). Look up your Congressional representatives at www.senate.gov and www.house.gov. Your voice can make a difference.

Take Part in Research

People are needed for clinical trials that can help find new treatments for neurologic disorders. Clinical trials are research studies. They help ensure that new drugs are both safe and effective. Ask your neurologist how to volunteer for a clinical trial. You can also find trials through patient organizations or the American Academy of Neurology website at www.aan.com/view/clinicaltrials.

Resources

American Academy of Neurology

www.aan.com/patients

(800) 879-1960

The American Academy of Neurology website for patients and caregivers offers a wealth of articles, information about events and resources, and links to support groups, clinical trial information, and more.

Neurology Now® magazine

www.neurologynow.com

(800) 879-1960

Free magazine for patients and caregivers, courtesy of the American Academy of Neurology. Stories about people living with neurologic disorders, the latest information on resources and treatments, and more.

ALS Association

www.alsa.org

(800) 782-4747

Les Turner ALS Foundation

www.lesturnerals.org

(888) ALS-1107 (257-1107)

Muscular Dystrophy Association

www.mdaua.org

(800) 572-1717

Project A.L.S.

www.projectals.org

(800) 603-0270



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The American Academy of Neurology, an association of 25,000 neurologists and neuroscience professionals, is dedicated to promoting the highest quality patient-centered neurologic care. For more information about the American Academy of Neurology, visit *www.aan.com*.

Cover photo courtesy of the ALS Association, MN/ND/SD Chapter