

ALS (AMYOTROPHIC LATERAL SCLEROSIS)

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ALS (AMYOTROPHIC LATERAL SCLEROSIS)

Caring for a loved one with ALS is no easy task. Not only does it require physically caring for someone you love at home, but it also means facing your own concerns about the diagnosis and eventual outcome of the disease. You may be concerned that there is no cure for your loved one's disease. You may also worry about how quickly the disease will progress.

Physical and emotional care can be time-consuming and exhausting. Most caregivers of people with ALS have concerns about their loved ones' illness and future health prospects. Practical concerns, such as worries about financial issues and time management, are also common. The goal of this chapter is to address some of these concerns.

Learning more about ALS is an essential first step in your caregiver role. This can be important for caregivers who are often caring for partners. It may be overwhelming to think of your loved one being helpless and dependent upon you. Understanding the disease and knowing what to expect can help you feel more in control.

It can be difficult to learn about a disease when you do not know where to start. This section provides general information about ALS, including what caregivers can do to help their loved ones.

What Is ALS?

ALS, also known as Lou Gehrig's disease, refers to a type of motor neuron disease. Motor neurons control muscles. Patients with the disease lose their ability to move as the neurons die.

As motor neurons die, the muscles they control begin to twitch and weaken (atrophy), eventually losing their ability to function. Patients with ALS lose strength all over their bodies. Eventually they may not be able to move or to breathe without assistance.

ALS does not affect the ability to think or remember. It will not affect the personality of your loved one. Although the patient may become frustrated and saddened by the disease, he/she will remain the person you have always known. He/she will be able to move the eye muscles and retain control of bladder and bowel functions. The senses of taste, touch, smell, sight and hearing also remain intact and can continue to bring great pleasure to your loved one.

(Adapted from a National Institutes of Health ALS Fact Sheet, August 2000)



Who Gets ALS?

According to the National Institutes of Health, about 20,000 people in the United States have ALS. An estimated 5,000 people per year are diagnosed in the United States. It affects all races and age groups, although it is more prevalent in men and in people aged 40 to 60 years old.

Your family members and friends may wonder if they can "catch" ALS from the patient. The disease is not contagious. It cannot be spread from person to person through the air, by contact or via blood transfusions. In about 5 to 10 percent of all cases, ALS is inherited. This means that it is passed through the family from parent to child. This is called familial ALS. In the other 90 to 95 percent of ALS cases, the cause is not known and no risk factors have been identified. This is known as sporadic ALS.

Common Symptoms of ALS

The following symptoms are common in people with ALS. However, it is important to know that these symptoms do not mean that the patient has ALS. Only a doctor can make a diagnosis.

ALS symptoms

- n Muscle weakness, wasting, cramping, and twitching
- n Slurred, slow speech
- n Difficulty swallowing
- n Slow and uncoordinated movements

(Adapted from Forshew, D. and Hulihan, S. Living with ALS:What's It All About?.ALS Association,1997)

Diagnosing ALS

Doctors use various means to make a diagnosis:

- s Evaluation of the patient's medical history.
- s Physical examination including a complete neurological exam.
- s Electromyogram (EMG) and nerve conduction velocity (NCV) check the health of the nerves and muscles.
- s Muscle biopsy – Where tissue is obtained through a needle or surgical procedure and directly examined.
- s Other tests such as magnetic resonance imaging (MRI) may be done to rule out conditions with similar symptoms.

(Adapted from information provided by the Muscular Dystrophy Association, 2001 and from a National Institutes of Health ALS Fact Sheet, August 2000)



Hearing that your loved one has ALS may be frightening. It is difficult to know how quickly the disease will progress. You may worry about whether he/she will suffer. This disease will eventually make your loved one dependent upon others for care. You may want to take care of him/her but wonder if you can. There is so much for you to think about, yet you might be reluctant to talk to your loved one about your worries. It is important that you get support when you feel like this.

For more information on obtaining support, taking care of yourself and using relaxation techniques, please see the "You Have Needs, Too" section.

Treatment for ALS

Although there is currently no cure for ALS, there are treatments that can slow the progression of the disease and improve its symptoms. Treatment options, some of which depend on the symptoms, include:

- n Drug therapy
- n Non-drug therapy



Drug therapy

Riluzole (Rilutek) is the first drug treatment approved by the Food and Drug Administration (FDA) for the treatment of ALS. This drug has been shown to reduce the damage ALS does to motor neurons. However, Riluzole does not reverse the damage already done. In clinical trials with ALS patients, Riluzole prolonged survival by several months. Patients on the drug also survived longer without needing ventilation support.

(Adapted from a National Institutes of Health ALS Fact Sheet, August 2000)

Non-drug therapy

Non-drug therapies can be very important for ALS patients. They can help improve patients' quality of life and provide relief for caregivers as well. Learning about the therapies, including when and where to obtain them, is a valuable way for you to help your loved one cope with ALS.

- n Physical and occupational therapy – exercises and special equipment can help with symptoms and make it easier for your loved one to move around.
- n Nutrition – a nutritionist can advise you on planning many small nourishing meals that can be served throughout the day.
- n Speech therapist – a speech therapist can help patients who are having difficulty speaking.
- n Relaxation techniques – learning how to relax can help patients cope better with the illness.

- n Massage – can decrease muscle stiffness and relieve the discomfort of cramps, and can also be quite pleasurable and relaxing for your loved one.
- n Distraction – engaging activities (such as hobbies, video games and movies) that change the patient’s focus can help relieve symptoms.
- n Psychotherapy – speaking with a mental health professional about the stress and frustration of ALS, and learning techniques for coping with the disease, can be beneficial for both you and the patient.

For more information on relaxation techniques, see the "You Have Needs, Too" section of this directory.

Treatment for disease-related symptoms

As ALS progresses, your loved one will develop new symptoms. The good news is that there are treatments for these symptoms. You can help by understanding each symptom and related treatment options. You can also help by knowing when to contact your loved one’s health care team.

For more information on how and when to effectively communicate with the health care team, please see the "Navigating 'The System'" section.

- s Muscle cramps and spasms – Stretching exercises, drinking plenty of liquids, and, in some cases, medication, can help.
- s Swelling of hands and feet – Elevating your loved one’s arms or legs may help with the swelling. If the problem persists, talk to the doctor.
- s Excess saliva and drooling – Medications can help dry out the patient’s mouth.
- s Clogged throat and/or nose – This may be caused by the patient breathing through his/her mouth more than usual. Using a room humidifier can sometimes alleviate the symptom. If it persists, talk to the health care team about medications.
- s Jaw quivering and/or teeth chattering – This symptom can occur when the patient is chilled, yawning, or speaking. If it becomes a problem, discuss appropriate treatment with the health care practitioner.
- s Brief periods of difficulty breathing – This symptom can scare both you and your loved one as he/she may gasp for breath or have feelings of suffocation. If your doctor tells you that this is a temporary symptom that may come and go, you might work together and try to find ways to help. For example, trying to breathe deeply, and getting fresh air from a window or fan can be beneficial. You can help your loved one avoid strong smells, such as smoke, cold air, alcohol, and spicy foods, if they bring on the symptom. You can also ask the doctor about medications that can help.

s Acid indigestion and heartburn – People with ALS and acid indigestion may have gastro-esophageal reflux disease (GERD). This can also cause coughing, bad breath, scratchy throat, hoarse voice, shortness of breath, nausea, and sleeplessness. You can help your loved one avoid things that cause indigestion such as caffeine, spicy foods, and overeating. Your loved one's doctor can suggest medication for GERD.

s Speech problems – ALS causes speech problems that can make it difficult for your loved one to communicate. Encourage him/her to speak slowly, pronounce carefully, and to get help from a speech therapist when needed.

Please see the "You Have Needs, Too" section for more information on the symptoms listed below. This section describes techniques that can help patients relax and cope with emotions.

s Sleep disturbances – You can help by encouraging the use of relaxation techniques to relieve stress. If your loved one continues to have difficulty with sleep, discuss this with the health care team.

s Depression and anxiety – These are understandable symptoms for ALS patients. You can ask his/her doctor about professional help and medication.

Please see the "Symptom Management at Home" section for information on the symptoms listed below.

- s Constipation
- s Fatigue
- s Shortness of breath

(Adapted from Gelinus, D. Living with ALS: Managing Your Symptoms and Treatment. ALS Association, 1997)



Clinical trials

Clinical trials are research studies that evaluate new treatments. Those who take part in clinical trials are some of the first to receive and benefit from new approaches to ALS therapy. These treatments have usually been tested with good results. Patients in trials are watched closely by physicians and researchers. For more information on how clinical trials and ALS research might benefit your loved one, contact the National Institutes of Health and/or the Muscular Dystrophy Association (see resource information at the end of this section).

Complementary or alternative therapy

Complementary and alternative therapies are treatments that do not use known ALS drugs. Rather, therapy comprises techniques not common in the medical community. Some complementary therapies (such as relaxation, visualization, and acupuncture) are so common that they are considered mainstream, and used along with traditional medical therapies. It is important to research and understand the risks and benefits of these therapies, and to discuss their use with the doctor.

The National Center for Complementary and Alternative Medicine (NCCAM) Clearinghouse (listed with the resources at the end of this section) is a good source of information for these approaches.

What You Can Do to Help

- n Learn as much as possible by reading and asking experts about ALS.
- n Find medical practitioners who understand the disease.
- n Ensure regular visits to the patient's doctor.
- n Ask questions of doctors and discuss your concerns.
- n Find ways to avoid and manage stress in the household.
- n Administer medications as prescribed.
- n Offer to massage sore or cramped muscles, if the physician approves.
- n Encourage your loved one to eat even when his/her appetite is poor.
- n Help the patient keep his/her mouth clean; brush teeth at least twice a day.
- n Encourage the use of techniques to relieve stress and promote symptom management.
- n Distract the patient with enjoyable activities to help decrease the effects of the disease symptoms.
- n Help rate and record fatigue in a fatigue journal.

Please see the "Symptom Management at Home" section for other information on fatigue (including keeping a fatigue journal). For more information on relaxation techniques, see the "You Have Needs, Too" section of this directory.



HELPFUL ALS RESOURCES

Organizations

n National Institute of Neurological Disorders and Stroke

NIH Neurological Institute

P.O. Box 5801

Bethesda, MD 20824

(800) 352-9424

http://www.ninds.nih.gov/health_and_medical/pubs/als.htm

- This is the primary National Institutes of Health organization for research on ALS. It provides excellent, up-to-date, and easy to understand information on the disease.

n ALS Association of America (ALSA)

27001 Agoura Road, Suite 150

Calabasas Hills, CA 91301-5104

(818) 880-9007

Patient hotline: (800) 782-4747

Fax: (818) 340-2060

<http://www.alsa.org>

- This is the only national not-for-profit voluntary health organization dedicated solely to the fight against ALS. It provides a library of free manuals on living with ALS and videos that you can borrow for a small fee to learn more about the disease. The material provided includes information on the management of disease-related symptoms. Some support group and caregiver information is also provided. The Website has a forum for sharing stories about the disease.

n The Muscular Dystrophy Association

3300 East Sunrise Drive

Tucson, AZ 85718-3208

(520) 529-2000

(800) 572-1717

<http://als.mdausa.org>

- This organization provides a comprehensive Website with information about the disease, research information (including clinical trials), an "Ask The Expert" service, online videoconferences, referrals to support groups and access to publications, including an excellent online caregivers' guide and an ALS newsletter. Information is also provided in Spanish.

n U.S. National Library of Medicine

8600 Rockville Pike

Bethesda, MD 20894

(888) FIND-NLM

(888) 346-3656

(301) 594-5983 (local and international calls)

<http://clinicaltrials.gov/ct/gui/action/FindCondition?ui=D000690&recruiting=true>

- This service, which is provided by the National Institutes of Health, posts information on ALS clinical trials.



n National Center for Complementary and Alternative Medicine (NCCAM)
Clearinghouse
P.O. Box 8218
Silver Spring, MD 20907-8218
Toll Free: (888) 644-6226
TTY/TDY: (888) 644-6226
FAX: (301) 495-4957
<http://nccam.nih.gov/>

- This is the National Institutes of Health organization dedicated to exploring complementary and alternative healing practices.

Websites

n MEDLINEplus Health Information
<http://www.nlm.nih.gov/medlineplus/amyotrophiclateralsclerosis.html>
● MEDLINE is a service of the National Library of Medicine that provides excellent links to Websites, journals, and abstracts for a variety of topics related to ALS.

n ALS Survival Guide

<http://www.alssurvivalguide.com/>

- This is a patient-run ALS Website. It provides a unique glimpse into the disease through the site founder's journal entries and the sharing of other ALS stories. The site also offers other information including an "Ask the Expert" service and some caregiver information.

Español/Spanish Information

n Hechos Sobre la Esclerosis Lateral Amiotrofica (ALS)
(Muscular Dystrophy Association)
<http://www.mdaua.org/espanol/esp-fa-als.html>

