The mission of The ALS Association is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig’s Disease and their families to live fuller lives by providing them with compassionate care and support.

Member of the National Health Council and National Organization for Rare Disorders
The original illustrations in this handbook depict the four primary programs of The ALS Association.

A message of hope

Tribute and memorial gifts represent a special and thoughtful way to honor someone in life and in memory. Celebrating people, their birthdays and accomplishments, special anniversaries and holidays, with a gift in support of the important work of The ALS Association offers those you care for, a message of hope.

The individual honored, or their family, receive notification of your thoughtfulness with a special letter.

To make such a gift, please contact The ALS Association at 27001 Agoura Road, Suite 150, Calabasas Hills, CA 91301-5104. You may also make a gift by calling us at 888-949-2577 or logging on to www.alsa.org/donate.

On the cover:

RESEARCH

What we see today may bring the answers to our questions tomorrow.
Join in the fight

In July 1939, when the great Lou Gehrig stood before thousands of fans in Yankee Stadium, weakened from early symptoms of ALS, he said, “...today, I consider myself the luckiest man on the face of the earth.” Lou Gehrig really meant that and his tears showed he meant it. He had friends, family and a loving public to help him through the last days of his life as the disease slowly destroyed him.

Today's ALS patients have The ALS Association with them as well, offering support and information, helping them to cope – physically, emotionally and intellectually, to live more productively and independently. The ALS Association is also deeply involved in fundraising activities, without which there could be no research, no patient care, no help.

The growing network of local chapters and support groups sustain The Association’s efforts at the grass roots level, fundraising for research and providing referrals, equipment loan programs and assistance to patients in their immediate areas.

There are many ways you can help, through your donations or by joining or forming a local group. Whatever you can do, the 15 individuals who are newly diagnosed as having ALS each and every day in the United States will thank you.

For further information about The ALS Association and its many activities, please write, call us or visit our website. Our contact info is located on the back cover of this brochure.

We live our mission everyday. The ALS Association is fighting on every front to improve living with ALS.

What is ALS?

Amyotrophic lateral sclerosis (ALS), often referred to as “Lou Gehrig’s Disease,” is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually lead to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed.

Amyotrophic comes from the Greek language. “A” means no or negative. “Myo” refers to muscle, and “Trophic” means nourishment—”No muscle nourishment.” When a muscle has no nourishment, it “atrophies” or wastes away. “Lateral” identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates it leads to scarring or hardening (“sclerosis”) in the region.
**Incidence of ALS**

ALS is one of the most devastating of disorders which affect the function of nerves and muscles. The incidence of ALS is about 2 per 100,000 population. This, based on the 2000 U.S. Census, some 5,600 people in the U.S. are newly diagnosed with ALS each year. (That’s about 15 new cases a day.) It is estimated that as many as 30,000 Americans may have the disease at any given time.

Most who develop ALS are between the ages of 40 and 70. There have, however, been many cases of the disease attacking persons in their twenties and thirties. Generally, though, ALS occurs in greater percentages as men and women grow older. Both sexes are affected in nearly equal numbers.

With recent advances in research and improved medical care, many ALS patients are living longer and more productive lives. Half of all affected live at least three years or more after diagnosis. Twenty percent live five years or more; up to ten percent will survive more than ten years.

**Forms of ALS**

The most common form of ALS in the United States is known as “sporadic” ALS. It may affect anyone, anywhere.

“Familial” ALS suggests the disease is inherited, although no heredity pattern is known to exist in the majority of ALS cases. Only about five to ten percent of all ALS patients appear to have some kind of genetic or inherited component. In those families, there is a 50 percent chance the offspring will have the disease.

Other terms which have been used to categorize variants of the classical form of ALS include spinal muscular atrophy, progressive bulbar palsy, and lateral sclerosis. Other variants of ALS whose prognosis is better and whose relationship to ALS is not yet determined include primary lateral sclerosis, juvenile muscular atrophy and benign facial amyotrophy.

**EDUCATION**

Awareness brings dedication
Dedication will bring the answers
Making the public and professionals aware

A strong public and professional education program is underway at The ALS Association. The medical community and all health care professionals need to be better informed about ongoing research, both biomedical and therapeutic, presently being conducted.

The Association is represented at annual meetings of the American Neurological Association, Society for Neuroscience, American Academy of Neurology and the American Association of Neuroscience Nurses to mention but a few. In addition to distributing literature and exhibiting displays explaining The ALS Association and its goals, ALS Association staff learn of the latest in ALS-relevant research and other information which would help forward its goals.

Educational conferences are also sponsored by The ALS Association for health care professionals, patients and their families on all facets of the disease and patient care.

A public awareness campaign includes articles, features and public service ads in major newspapers and magazines and on radio and television.

Besides other pertinent printed materials there is also *A Reason for Hope* magazine, The ALS Association’s national publication. *Hope* magazine features articles on all facets of the organization and significant news and developments in the fight against the disease.

The ALS Association conducts a year-round, network-wide advocacy program from its Capital Office in Washington, D.C. The overall goal is to advocate for public policy in support of ALS and ALS-related health care issues, including accelerated treatment development and access to proper care and treatment.

PATIENT SERVICES

An open hand and heart for love
An open mind for understanding
Symptoms of ALS

Early symptoms vary with each individual, but usually include tripping, dropping things, abnormal fatigue of the arms and/or legs, slurred speech, muscle cramps and twitches and/or uncontrollable periods of laughing or crying.

The hands and feet may be affected first, causing difficulty in lifting, walking or using the hands for the activities of daily living such as dressing, washing and buttoning clothes.

As the weakening and paralysis continue to spread to the muscles of the trunk of the body the disease, eventually affects speech, swallowing, chewing and breathing. When the breathing muscles become affected, ultimately, the patient will need permanent ventilatory support in order to survive.

Since ALS attacks only motor neurons, the sense of sight, touch, hearing, taste and smell are not affected. For many people, muscles of the eyes and bladder are generally not affected.

In most cases the mind is not impaired and remains sharp despite the progressive degenerating condition of the body.

Diagnosis of ALS

ALS is a very difficult disease to diagnose. To date, there is no one test or procedure to ultimately establish the diagnosis of ALS. It is through a clinical examination and series of diagnostic tests, often ruling out other diseases that mimic ALS, that a diagnosis can be established. A comprehensive diagnostic workup includes most, if not all, of the following procedures: electrodagnostic tests including electromyography (EMG) and nerve conduction velocity (NCV), blood and urine studies including high resolution serum protein electrophoresis, thyroid and parathyroid hormone levels and 24 hour urine collection for heavy metals, spinal tap, x-rays, including magnetic resonance imaging (MRI), myelogram of cervical spine, and muscle and/or nerve biopsy.

Response to patient concerns and needs

The Association’s Medical Advisory Committee, including interdisciplinary representation of medical experts in the diagnosis and management of ALS, provides advice and counsel to The Association regarding patient care, merits of therapeutic claims, unorthodox treatments and information disseminated by The ALS Association.

The Association is a vital link for patients and their families to information and resources through its national and local patient services programs. In addition to referral services The ALS Association offers:

- The Information Bank
  1. “FYI” — Provides current definitive answers to specific questions about management of the disease as well as address the difficult and psychological issues of caring for ALS patients.
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- Living With ALS manuals and DVD
  Commissioned and compiled by The Association, this particularly vital resource consists of six “Living with ALS” manuals and one DVD. These six manuals deal with the specific needs encountered by nearly every ALS patient and their caregiver. The manuals are seen as the international standard and complete guide to care of ALS patients.
Research through The Association

The ALS Association drives ALS research through 1) funding international research programs from basic to clinical research, 2) the organization of scientific workshops to stimulate scientific collaborations and bring new scientists to the ALS field and 3) rapid translation of findings into clinical trials for ALS patients.

The ALS Association’s TREAT ALS (Translational Research Advancing Therapy for ALS) initiative combines efficient new drug discovery with priorities set for existing drug candidates, to accelerate clinical testing of compounds with promise for the disease. Already partnering with many organizations around the world including The National Institutes of Health (NIH), The ALS Association brings together an expert team of scientific and business advisors to steer this import drug discovery program.

Twice annually, The ALS Association invites researchers to submit proposals for consideration. The Association awards multi-year and starter grants as well as an annual post-doctoral fellowship. At any given time there are approximately 100 Association-funded research studies in progress. The ALS Association also initiates scientific studies through its ALS Association-initiated research program. Launched in 2000, this effort complements and works in tandem with the investigator-initiated research by engaging established investigators with extensive expertise and applying the most advanced technology to answer the more complex questions about ALS.

ALS focused workshops for the scientific community are hosted by The ALS Association during the year to advance current knowledge about the mechanisms and cause(s) of ALS, attract more neuroscientists to ALS research and foster collaborative research.

The Association’s Clinical Management Research Program, administered through Patient Services, focuses on managing the care of ALS patients in such areas as nutrition, respiration, mobility and psychosocial needs. These tests are done at the discretion of the physician, usually based on the results of other diagnostic tests and the physical examination.

There are several diseases that have some of the same symptoms as ALS and most of these conditions are treatable. It is for this reason that The ALS Association recommends that a person diagnosed with ALS seek a second opinion from an ALS “expert” - someone who diagnoses and treats many ALS patients and has training in this medical specialty. The ALS Association maintains a list of recognized experts in the field of ALS. This is not meant to imply that other neurologists cannot make a diagnosis, only that physicians referred by The Association see many ALS patients.

The search for answers

The cause, cure or means of prevention of ALS are presently unknown. The disease was first described in detail in 1869 by the noted French neurologist, Jean-Martin Charcot. Subsequently research has been unable to pinpoint the cause of ALS, but a number of hypotheses have been advanced.

Some of these have dealt with infectious causes, the autoimmune function, heredity, toxic substances, chemical imbalances in the body and nutrition. More recent scientific studies suggest excitotoxic injury of motor neurons, free-radical-mediated oxidative injury to nerve cells, inflammation and immune response, premature programmed cell death (perhaps as a result of the first three items), environmental factors and “risk” or susceptibility genes. Many investigators now believe that the answer to ALS will be multifaceted.

Treatment today

Although there is not yet a cure for ALS, much can be done not only to help patients live with the disease, but live more productively and independently.
The concept of ALS as a hopeless disease is fast giving way to an approach that emphasizes the treatment of a patient’s symptoms. This can improve the quality of life for the patient and help them develop a positive attitude about being part of the management care team.

Physical therapy, rehabilitation techniques, and assistive devices are helping patients learn how to work around the weakness and functional disability caused by the disease.

In addition, studies have revealed that some compounds may alter the progression or course of ALS. Rilutek® was approved in 1995 as the first drug to alter the course of the disease.

There is information available today. There is direction. There is hope.

**What is The ALS Association**

The ALS Association is the only national not-for-profit health organization dedicated solely to lead the fight against ALS. The Association covers all the bases - research, patient and community services, public education, and advocacy - in providing help and hope to those facing the disease.

The mission of The ALS Association is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig’s Disease and their families to live fuller lives by providing them with compassionate care and support.

In the quest to create a world without ALS, our vision is to care for and support all people living with Lou Gehrig’s Disease as we leave no stone unturned in our relentless search for a cure.
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