

Living with ALS

By Rebecca Mayer Knutsen

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease with no known cause, cure or medical treatment. The invariably fatal disease attacks the nerve cells (neurons) responsible for controlling voluntary muscles, such as those in the arms, legs and face. ALS, also known as Lou Gehrig's disease, is a rare disease with about 5,000 new cases diagnosed in the U.S. each year.

With a multidisciplinary care approach and advancements in technology, the quality of life and survival rate of patients living with ALS have improved. Molecular biologists, specialists and genetic researchers have made tremendous progress in understanding who and why this disease strikes but still have a long way to go in finding a cure.

SYMPTOMS:

Identifying and addressing problematic symptoms is a major component of caring for patients with ALS. No two patients with ALS will present in exactly the same way or exhibit the same symptoms. Proper care can minimize the effects of symptoms on a person's function, health and quality of life.

Because the onset of ALS is subtle, symptoms are often overlooked in the beginning stages of the disease. Early symptoms can include muscle twitches, cramps, spasticity, muscle weakness in arms or legs, slurred and nasal speech, or difficulty chewing or swallowing. Muscle weakness is the most significant symptom affecting patients with ALS. The course of disease progression varies widely from patient to patient but complications may include respiratory issues, paralysis and difficulty swallowing.

DIAGNOSIS:

There is no single diagnostic test available to identify a patient with ALS. A neurologist will evaluate a patient's past health, symptoms and disease presentation and run tests to rule out diseases that present with similar symptoms. Nerve conduction velocity (NCV) and electromyography (EMG) are the most common tests administered when ALS is suspected. NCV measures the speed at which nerves transmit



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electrical signals and EMG measures nerve impulses within the muscles. Other diagnostic tests that may be performed include: magnetic resonance imaging, laboratory and urine tests and lumbar puncture.

HEALTHCARE TEAM:

Learning that you have ALS can be overwhelming and isolating, but you are not alone. Healthcare providers, caregivers, family members and others diagnosed with ALS will be with you every step of the way to provide guidance, care, patience and resources. The multidisciplinary healthcare team you will encounter will include the following practitioners and professionals:

- Physicians
- Nurses
- Speech-Language Pathologists
- Physical and Occupational Therapists
- Social Workers
- Dieticians
- Respiratory Therapists

TREATMENT:

There is no cure or medical treatment for ALS, but researchers are working feverishly to understand the etiology and pathogenesis of the disease. Riluzole was approved by the FDA in December 1995 for the treatment of ALS. Riluzole is the first drug shown to provide some benefit, although rather limited, to people with ALS.

The most significant changes to the quality of life for those with ALS have come from technological advancements. Patients with ALS

can mitigate many of their physical symptoms through mechanical or computerized devices, including power wheelchairs and augmentative and alternative communication devices.

With the help of supportive devices and equipment such as canes, walkers, raised toilet seats and shower seats, patients with ALS can be mobile, communicate and accomplish daily tasks like bathing, eating and dressing. These devices help combat fatigue, which is an ongoing and progressive issue for those with ALS.

CARING FOR CAREGIVERS:

The family members and friends who care for patients with ALS can face their own issues, stemming from the diagnosis. It's not uncommon for caregivers to suffer from depression, fatigue and anxiety due to the burden of increasing daily tasks as well as the overwhelming fears associated with the ALS diagnosis. Many ALS clinics offer resources and support groups to help manage the mental and physical health of these caregivers.

This handout was reviewed by Merisa Palovcak Allen, MS, CCC-SLP/L, a speech-language pathologist at the University of Pennsylvania's ALS Clinic, and is based on information obtained from the ALS Association at www.alsa.org, the Muscular Dystrophy Association at www.mda.org and the National Institute of Neurological Disorders and Stroke at <http://www.ninds.nih.gov>.

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