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Part 1 Amyotrophic Lateral
Sclerosis (ALS) Overview

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Amyotrophic Lateral Sclerosis (ALS): Introduction

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Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease which affects the brain and the spinal cord, or the central nervous system (CNS), and the peripheral nerves of the peripheral nervous system (PNS). ALS also is known as Lou Gehrig's disease, named after the Yankees baseball player who died of it in 1941. ALS is a progressive and fatal disease with no known cure.

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How does ALS affect the body?

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In a healthy body, the upper motor neurons in the brain send messages to the motor neurons in the spinal cord and to the motor nuclei of the brain (also known as the lower motor neurons). Those messages are then sent from the spinal cord and the lower motor neurons to a particular muscle or muscle group. In persons with ALS, both the upper and the lower motor neurons degenerate or die. The neurons can no longer send messages to the muscles, which gradually weaken and atrophy. Eventually, this leads to the paralysis of all voluntary muscles, including those used for chewing, swallowing, and breathing.

Who Gets ALS?

The causes for ALS are unknown. About 1 out of 10 people with ALS have other family members who have had ALS. This condition is called familial ALS (fALS), caused by a mutation in a gene. ALS is an equal opportunity disease — it affects people of all races and ethnic backgrounds. ALS usually strikes most commonly between the ages of 55 and 75. Men are slightly more likely to develop ALS than women.

Symptoms

The symptoms of ALS can be limited to one or more regions of the body. Usually, ALS can appear as muscle weakness in the hand, arm, or leg. Muscle twitches and cramps are common. When ALS begin in the arms or legs, it is referred to as “limb onset” ALS. When a person’s speech or swallowing is first affected, it is known as “bulbar onset” ALS.

ALS can cause the following:

- Coordination issues
- Muscle weakness, stiffness
- Muscle spasms
- Fatigue
- Paralysis
- Difficulty breathing
- Difficulty swallowing, including choking, gagging, drooling
- Speech problems, slurring of words
- Voice changes
- Weight loss
- Possible mild cognitive degeneration
- Possible behavioral abnormality

Some ALS patients do develop ALS-related dementia which presents itself as difficulties with memory, language, and decision making. Because ALS is a disease of motor nerve, typically ALS does not cause pain. However, some ALS patients experience some pain due to lack of muscle movement.

Treatment

There is no treatment toward a cure, however, some medications can ease symptoms.

Riluzole (Rilutek) is a glutamate blocker.

Muscle relaxants can help reduce muscle tension and help relieve pain

Life Expectancy

According to information provided by the Emory University School of Medicine, most ALS patients die peacefully in their sleep. Most die from respiratory failure. The life expectancy is three to five years from diagnosis, however, approximately 10 percent of people with ALS have a survival rate of 10 or more years.

Tip Sheet

ALS affects voluntary muscles, ALS can affect speech and swallowing, causes of ALS are unknown, there is no cure for ALS

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Part 2 Central and Peripheral Nervous Systems

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The Neurological System

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The Neurological System is divided into two major parts: the **Central Nervous System (CNS)** and the **Peripheral Nervous System (PNS)**.

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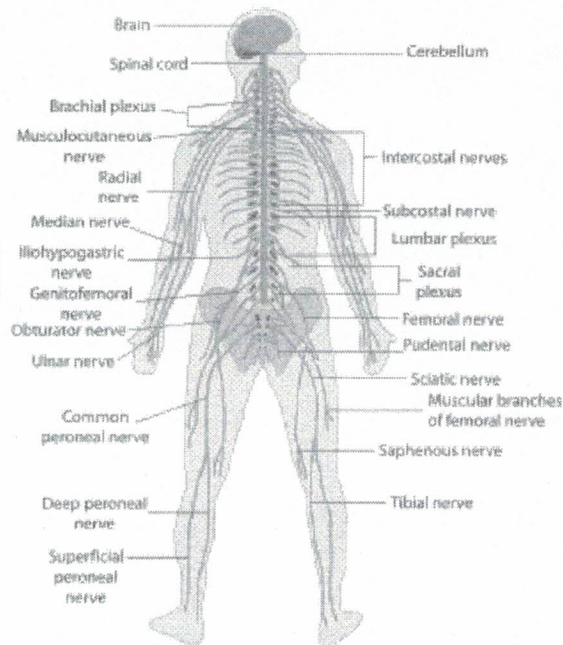
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The Central Nervous System (CNS)

The central nervous system is the headquarters of the body, governing almost all of its functions. The CNS is made up of the **brain** and the **spinal column**.

The Brain

See, Hear, Smell, Taste, Touch: All of these tasks are performed by your body's "sense organs": eyes, ears, nose, tongue and skin. The nerves in these sensory organs receive and deliver information, or impulses, from the environment around you to the brain. The brain processes these signals and makes decisions based upon them. The signals can act as warning signs and help us maintain our safety in

our external and internal environment. The brain is also the center of all thoughts and decision-making, language and communication, emotion, memories, and dreams.

The Spinal Cord

The spinal cord is a bundle of nerve fibers that connects the brain to the peripheral nervous system. It is the pathway that sends signals to and from the brain, to and from the rest of the body. It extends from the base of the skull down through the center of the spinal column, which is designed to protect the spinal cord.

The Peripheral Nervous System (PNS)

The Peripheral Nervous System is the nervous system outside the brain and the spinal cord. The PNS connects the CNS to the limbs and organs, communicating back and forth between the brain and spinal cord with and the rest of the body.

The PNS includes:

The Somatic Nervous System (SNS) – Responsible for all voluntary skeletal muscular activities we consciously control.

The Autonomic Nervous System (ANS) – Responsible for all activities that occur automatically and involuntarily, such as breathing, muscle contractions within the digestive system, and heartbeat, or the work of the smooth and cardiac muscles.

Tip Sheet

Pathology and anatomy of the nervous system.

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Part 3 Caring for Persons with
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Caring for a person with ALS

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There is no known cure for ALS, but therapy can help manage some effects of the disease. As a caregiver, be prepared to take your senior client to the following therapists as an outpatient or have therapists treat clients in-home. Most progressive diseases such as ALS takes a team of caregivers to provide comprehensive care.

Therapies

Physical—a trained physical therapist can evaluate and treat problems associated with movement, especially difficulty with balance, walking, endurance, transfers, or functional activities. They can also suggest assistive devices or equipment that will help with daily activities in the home. In general, physical therapy will help prevent joint stiffness and maintain joint mobility. maintain the health of lungs and heart as much as possible delay muscle atrophy maintain independent mobility for the person with ALS by recommending assistive devices such as braces, canes, and walkers. As the disease progresses, lifts, wheelchairs, and other special equipment can help caregivers keep their clients connected and engaged.

Occupational — Occupational Therapists (OTs) can help keep clients with ALS to be more independent longer by providing exercises and education to assist with the activities of daily living such as eating, bathing, dressing, writing, cooking and shopping for as long as they are able. They can train a caregiver and patient to use adaptive devices such as button hooks, key holders, tub transfer seats, raised toilet seats, and lifting cushions.

Speech — A speech therapist can help ALS patients keep their speaking ability for as long as possible, with strategies to speak louder and more clearly. However, even after an ALS patient loses their speech, they can still communicate and a speech therapist can recommend assistive communication devices. These can range from simple boards to computer-based speech synthesizers to eye-tracking technology. You can also develop alternative ways of communicating with your

client. They can respond to simple yes-or-no questions with their eyes or with other nonverbal cues.

Psychological — Of course, progressive diseases like ALS, especially ones that are terminal, can cause a patient to lapse into depression. Psychological help can address some of these challenges.

Nutritional Support — Keeping up weight in ALS patients is integral to staying healthy. Caregivers should know how to plan and prepare small meals throughout the day that provide enough calories and fluid and how to avoid foods that are difficult to swallow. When ALS patients can no longer get enough nourishment from eating, a feeding tube may be inserted into the stomach. This reduces the risk of choking and pneumonia that can result from inhaling liquids into the lungs. A Nutritionist can help with education and expectations.

Breathing Support — Clients with ALS may begin to experience shortness of breath as the disease progresses. Noninvasive ventilation (NIV) through a mask may be necessary. Some patients and their families may choose a tracheotomy, or an incision in the windpipe to help with breathing. While caring for an ALS patient may be minimal at the outset, as the disease progresses and independence becomes limited, the client may require 24/7 care. Discuss this with your Care Manager.

Here are some of the duties you can expect to perform as an in-home caregiver to a person with ALS:

- Medication Assistance
- Preparing meals and feeding
- Personal assistance with bathing, grooming, and other ADLs (activities of daily living)
- Assisting with mobility, helping to prevent trips and falls.
- Preventing pressure sores
- Providing transfer assistance
- Performing light housekeeping
- Running errands
- Maintaining communication

Being a caregiver to a client with ALS can be taxing. For that reason, you are encouraged to learn more about the disease in order to assist your client and to maintain your own health. Information provided by the following organizations can be extremely helpful.

Links to Supportive Organizations

ALS Association (ALSA)
www.alsa.org

The ALS Center at UCSF
<http://neurology2.ucsf.edu/brain/als/>

Tip Sheet

It can take a team of professionals to assist with the needs of the person with ALS.

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