Midlands Family Medicine
Let our family care for yours!

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Education

Amyotrophic Lateral Sclerosis (ALS)

What is amyotrophic lateral sclerosis (ALS)?

ALS is a disease that causes gradual weakness and loss of control of muscles. The mind is usually not affected, despite worsening weakness of the body.

ALS is also called Lou Gehrig's disease, after a well-known baseball player who died of ALS. It is rare. About 1 new case per 100,000 people is diagnosed each year. Symptoms most often appear in people who are between 40 and 70 years old. The symptoms worsen more rapidly in some people than in others, eventually leading to death.

How does it occur?

ALS affects the nerves in your brain and spinal cord that control your muscles. These nerves break down and disappear. Your muscles then become weak and waste away because the nerves that stimulated them are gone.

The cause of ALS is not known. It seems to run in some families. Also, some ethnic groups, such as Pacific Islanders, appear to be at greater risk. However, ALS most often occurs in people who have no family history of the disease.

What are the symptoms?

The symptoms are similar to other chronic (long-lasting) conditions affecting the central nervous system (brain and spinal cord). You may have:

- muscle cramps and twitching
- weakness in your hands and painless difficulty with small tasks, such as fastening buttons, turning a key, or opening a door
- weakness in your feet and ankles, causing your feet to drag when you walk (called foot drop)
- stiffness in your arms and legs
- slurring or slowing of speech
- difficulty swallowing
- decreased ability to make facial expressions
- fatigue
- weight loss.

The disease begins slowly, most often affecting just one limb, such as a hand, at first. As time passes, more limbs and muscle areas become affected.

As your disability increases, you become more dependent on others. Eventually you may be able to move only your eyes. To others it may look like you are in a coma, but you usually remain fully conscious and aware of your surroundings. You are still able to see, hear, taste, smell, and recognize touch. Bowel and bladder control and function are usually not affected. You may become too weak to breathe without the help of a ventilator. Respiratory failure, pneumonia, or blood clots in the lungs may cause death.

How is it diagnosed?

There is no specific test for ALS. Your health care provider will examine you, take your medical history, and order tests of your brain and nervous system. An electromyogram (EMG) may be done to test your muscles and nerves. Other tests done to rule out other diseases may include a computed tomography (CT) scan, magnetic resonance imaging (MRI) scan, muscle and nerve biopsies, and blood tests.

How is it treated?

There is no cure for this disease. Researchers are developing and testing new drugs that they hope will improve the treatment of ALS.

One medicine, riluzole (Rilutek), is sometimes used for treatment. It does not cure ALS, but for sometimes it slows the course of the disease. Ask your health care provider if riluzole would be recommended in your case.

During the early stages, treatment focuses on quality of life. Successfully managing this disease will allow you to live the fullest life possible. Depending on your condition, braces, walkers or a wheelchair may help. The home may need changes to accommodate lost mobility. There are drugs that help control drooling and spastic movement. Physical therapy may slow the loss of muscle tone. A feeding tube may be needed if swallowing problems become severe.

As the disease progresses, you may need to stay in a nursing home if you cannot be cared for at home.

Discuss with your family, friends, and health care providers how much should be done to maintain your life during advanced stages of the disease. What medical measures do you want to be taken at various stages of the disease? Do you want feeding tubes and ventilators to be used? Many people fear becoming unable to move, eat, or communicate at the end of life and may choose to limit life-sustaining treatments. These are difficult decisions. You and your family may want the help of clergy or other counselors to help you with these discussions.

What can I do to help myself?

Take care of yourself. For example:

- Maintain good emotional health with support from your family, friends, and clergy.
- Maintain a healthy lifestyle, which includes eating a balanced diet and getting regular exercise for as long as possible.
- Learn all you can about ALS. For additional information contact: Amyotrophic Lateral Sclerosis Association Phone: 800-782-4747 Web site: http://www.alsa.org.