

What is ALS?

ALS

Understanding symptoms and care of patients with ALS (pALS)

What is ALS?

amyotrophic lateral sclerosis (ALS)

- A progressive, neurodegenerative disease
- 100% fatal

Breaking it down:

“a” means no or negative +
 “myo” refers to muscle +
 “trophic” means nourishment =
 “no muscle nourishment.”

“lateral” is the area in the spine where the brain tells the muscles what to do.

“sclerosis” is hardening: as the disease progresses, the lateral areas harden and the signals stop.

ALS ASSOCIATION

ALS

Nervous system disease that weakens muscles and impacts physical function

ALS was founded in 1869 by French neurologist Jean-Martin Charcot. It stands for Amyotrophic Lateral Sclerosis (ALS) and is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord. These nerve cells (neurons) are responsible for controlling voluntary muscle movement such as: chewing, walking, and talking. In ALS, both the upper motor neurons and lower motor neurons degenerate and stop sending messages to the muscles.

Eventually, the brain loses its ability to control these voluntary movements. This disease is progressive, meaning the symptoms get worse over time. Most people with ALS have complications and go into respiratory failure. ALS came to national attention in the United States in 1939 when Lou Gehrig's baseball career ended due to his diagnosis. The majority of ALS cases are considered sporadic meaning the disease seems to occur at random with no clearly associated risk factors and no family history of the disease. Only about 5-10% of cases are familial meaning that they inherited it. The familial form usually only requires one parent to carry the gene responsible for ALS.

MOTOR NEURON

Nerve cells in the brain and spinal cord that attach to muscles and control voluntary movement

Effects of ALS on the body:

For many people, the first sign of ALS may appear in the hand or arm as they have difficulty performing simple tasks such as buttoning a shirt. Early signs also include muscle cramps, twitching, weakness in the extremities, and difficulty speaking or swallowing. Individuals may develop problems with moving, swallowing, speaking or forming words, and breathing. Due to having difficulty swallowing and chewing food, they have a higher risk for choking. Another complication for an individual with ALS is difficulty breathing as the muscles of the respiratory system weaken. Eventually they lose the ability to breathe on their own and depend on a ventilator. Breathing issues may also become worse during physical activity, or when lying down.

Things to Consider in the 9-1-1 Center:



Most individuals with ALS retain their ability to perform higher mental processes such as reasoning, remembering, understanding, and problem solving. This means they are aware of their loss of function. In addition, caregivers have specific instructions on when they are able to lay a patient down or what type of medications are appropriate. If a caller states that they are unable to lay an ALS patient down due to their breathing condition, it is okay to move forward and provide the rest of patient care instructions. We should not lay down an alert patient having difficulty breathing in any situation. This could make the breathing difficulty worsen and cause respiratory failure. Calls received from the individual with ALS, they can communicate multiple ways including a text-to-speech application. Be sure to give enough time during questioning for them to answer completely.

Some of these patients have also set up medical advanced directives and have do not resuscitate



This lesson is worth .5 CDE hours

(DNR) orders as well as medical orders for scope of treatment (MOST) on hand. Be sure to follow the agencies policies and procedures related to these types of situations.

MORE RESOURCES

ALS Worldwide: <http://alsworldwide.org>

The ALS Association: www.alsa.org

Colorado Advanced Directives:

<http://coloroadvancedirectives.com/wp-content/uploads/2014/07/1-MOST-Form-FINAL-2015.pdf>

The ABC's of ALS: www.thealsexpress.com/the-abcs-of-als/

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