



## El Paso – Teller County 9-1-1 Authority

<b>Policy Number</b>	<b>Policy Title</b> ALS CDE	<b>Reference</b> Authority Board
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### ALS CDE Quiz

- Should an alert patient with difficulty breathing be told to lie down?
  - Never
  - Always
- What does sporadic mean when being diagnosed with ALS?
- What does ALS stand for?
- What are two complications ALS patients may have when they activate 911?
- What can cause respiratory insufficiency in ALS patients?

#### Resources:

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

Colorado Advanced Directives: <http://coloroadvancedirectives.com/wp-content/uploads/2018/07/1-MOST-Form-FINAL-2015.pdf>

The ABC's of ALS: [www.thealsexpress.com/the-abcs-of-als/](http://www.thealsexpress.com/the-abcs-of-als/)

--This lesson is worth .5 CDE Hours--

# ALS

## Understanding symptoms and care of patients with ALS (pALS)

### What is ALS?

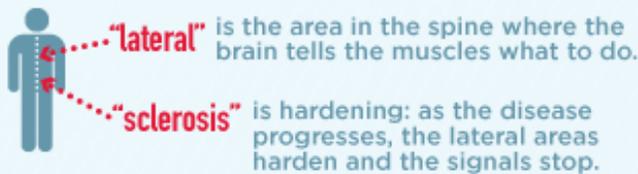


#### amyotrophic lateral sclerosis (ALS)

- A progressive, neurodegenerative disease
- 100% fatal

#### Breaking it down:

- "a" means no or negative +
- "myo" refers to muscle +
- "trophic" means nourishment =
- "no muscle nourishment."



### ALS

Nervous system disease that weakens muscles and impacts physical function

French neurologist Jean-Martin Charcot named ALS in 1869; it stands for Amyotrophic Lateral Sclerosis (ALS). ALS 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, talking, and breathing. 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 gets 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 NERON

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



## Effects of ALS on the body:

Patients with limb onset of ALS will first notice problems with walking or the use of hands. They have difficulty performing simple tasks such as buttoning a shirt. Bulbar onset pALS will first notice issues with speech or swallowing. Early signs include muscle cramps, twitching, and weakness in the extremities as well as problems with moving, swallowing, breathing, and speaking or forming words. Do not mistake speech issues with mental infirmity, the majority of pALS retain their full mental capacity. Another complication for an individual with ALS is difficulty breathing as the muscles of the respiratory system weaken. Depending on the patient's degree of disease progression, breathing ventilation may be Non Invasive (NIV) using face, nose masks, or a sip-n-puff mouthpiece, or may involve a tracheostomy. Breathing issues 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 worse and cause respiratory failure. Breathing issues in pALS are not due to oxygen absorption issues as with COPD, the problem is lack of air exchange resulting in carbon dioxide (CO<sub>2</sub>) retention. Administering oxygen is normally contraindicated which is why mechanical ventilation and using the patient's ventilator is recommended. When pALS call 9-1-1, 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 common reasons for pALS or their caregivers to activate the 9-1-1 system are falls, respiratory insufficiency/respiratory tract infections. ALS most often leads to quadriplegia, losing the ability to move, breathe without mechanical support, swallow or speak. Many caregivers cannot lift the patient unassisted; this creates safety issues with transferring the pALS to bed, a recliner or their wheelchair and can lead to injury of the patient. Respiratory insufficiency is a result of diaphragm and other muscle weakness. Generally, if there are no other pre-existing conditions, the lungs are healthy. Some of these patients have also set up medical advanced directives and have do not resuscitate (DNR) orders as well as medical orders for scope of treatment (MOST) on hand. Follow your agency policies and procedures related to these types of situations.

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