



Breathing Difficulties

ALS varies greatly from person to person and symptoms related to your breathing can start early or much later. Weakness in the muscles of respiration (breathing) can lead to a variety of symptoms.

Symptoms to Consider:

- ☐ Air “hunger” (gasping, labored breathing) with and without activity
- ☐ Fatigue
- ☐ Frequent yawning or sighing during the day
- ☐ Waking up in the morning with a headache or fuzzy headed feeling (morning confusion)
- ☐ Awakening frequently during the night (insomnia)
- ☐ Difficulty lying flat

ALS and Your Lungs

When you breathe in and out you need to be able to expand and relax the muscles in your chest. The diaphragm is a large dome-shaped muscle that separates your lungs from your abdomen (stomach). The muscles between the ribs are also involved in the breathing process. When the diaphragm moves down and the muscles of the rib cage contract, air will move into your lungs. The movement of air in and out of your lungs is called “ventilation.”

When you exercise, the muscles in the body use more oxygen. Therefore, the muscles of ventilation must also work harder to supply more oxygen to the muscles. If your respiratory muscles are weak, you may not be able to keep up with the demand. The end result is shortness of breath.

When you are sleeping, your body does not require the same amount of oxygen. As a result, the breathing cycle changes, breathing becomes slower and shallower. This is fine if you have normal lung function. However, if you have any respiratory muscle weakness breathing can become even more shallow. This may lead to frequent awakenings during the night. Your brain will tell your body to wake up and take a breath! You may or may not be aware of this phenomenon.

When you are lying down the strength of your diaphragm to push stomach contents away from your lungs is very important. If this muscle is weak, you may notice that lying down is no longer comfortable and you may feel restless or short of breath.





Medications can affect breathing: Medications that you take for pain, sleeping, anxiousness and or muscle stiffness may depress the breathing centers in the brain. It is important to let your physician know the names of all the medications you are taking (both prescription and over-the-counter drugs). Also, let him/her know that you are experiencing problems breathing.

Respiratory infections can affect breathing: The passageway (nose, throat, lungs) that air moves through can become blocked or constricted (narrowed) anywhere along its path. Nasal congestion can obstruct the upper airway. The bronchi (tubes moving air in and out of lungs) can become swollen so that air movement is restricted, thus making it even more difficult to breathe.

Methods to Reduce Shortness of Breath and Respiratory Complications

Positioning: Elevating the head of the bed may be sufficient at night. This can be accomplished by using extra pillows under the head, neck and chest. Elevating the head of the bed with pillows/blanket under the mattress, or between the mattress and box springs, or placing blocks under the headboard can also help.

Energy conservation: Set time aside during the day to rest between activities. Space your activities apart (bathing, dressing, eating, etc.). Reduce unnecessary steps, plan in advance. Sit down, when possible, to do the activity. Ask for help with the task you are trying to do if it causes shortness of breath. You may have more energy in the morning than later in the day. Therefore, plan your daily activities around your energy level.

Breathing exercises. Breathing and coughing techniques can help maintain healthy lung function. Deep breaths help to fully expand the lungs: take 5 to 10 deep breaths, with a short rest in between, several times a day. Coughing techniques are explained in The ALS Association's *Living with ALS manual #6* "Adapting to Breathing Changes."

Equipment: Portable suction can help remove secretions from the mouth. The **Cough Assist** device is now approved for reimbursement by Medicare. This device can assist you to remove secretions from your lungs by enhancing the strength of your cough. **Noninvasive ventilation** can assist with breathing, by helping you to expand your lungs with minimal effort. It has proven to be very beneficial at night to reduce insomnia and other symptoms of sleep deprivation. **Invasive ventilation** requires the insertion of a tracheostomy tube in the neck. This form of ventilation is used when the upper airway is obstructed and/or there is severe respiratory weakness and difficulty clearing secretions.





Risks – Respiratory Complications

Clearing secretions: A poor cough reflex can lead to pooling of secretions in the lungs and the back of the throat. This can lead to upper airway obstruction and/or respiratory infections, such as pneumonia.

Frequent coughing: Excessive ineffective coughing can lead to fatigue, shortness of breath and ultimately exhaustion.

Prevention Considerations:

- ☐ Avoid people who have symptoms of a cold or flu.
- ☐ Schedule your annual flu shot, and every four years your separate pneumonia shot.
- ☐ Discuss with your physician the use of medications to control excessive salivation and frequent coughing, breathing exercises, and alternative therapies.

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The ALS Association thanks Ms. Sepulveda for her contribution to this FYI.

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