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 associated with weak respiratory muscles:

- Air “hunger” (gasping, labored breathing) with an without activity
- Fatigue
- Frequent yawning or sighing during the day
- Waking 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

Breathing in and out is a result of contracting and relaxing the muscles in your chest. The diaphragm is a large dome-shaped muscle that separates your lungs from your abdomen (stomach). The diaphragm does most of the work to move air in and out of your lungs. The muscles between the ribs (intercostal muscles) are secondary muscles that support the breathing process. When the diaphragm contracts (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 and create more carbon dioxide. The muscles of ventilation must also work harder to supply the oxygen and remove carbon dioxide. 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, becoming slower and shallower. Secondary muscles may not respond during certain portions of the sleep cycle. If you have any respiratory muscle weakness breathing can become even more excessively shallow. This may lead to frequent awakenings during the night. You may or may not be aware of this phenomenon.
When you are lying down the diaphragm must push your abdominal contents away from your chest with each contraction, increasing the effort required to take each breath. 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 if you are experiencing problems breathing, or shortness of breath during any portion of the day or night.

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, making is even more difficult to breathe.

**Decrease work of breathing and promote airway clearance**

Positioning: Elevating the head of the bed. 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 while completing activities of daily living. Ask for help with the tasks 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. Breath stacking and specific coughing techniques increase lung volumes and improve effective coughing. Techniques are explained in The ALS Association’s Living with ALS manual #6 “Adapting to Breathing Changes.”

**Equipment to support ventilation and airway clearance:**

- Portable suction units can help remove secretions from the mouth
- A mechanical Cough Assist unit can assist in removing secretions from your lungs by enhancing the strength of your cough
- Noninvasive ventilation can assist with breathing by helping to expand your lungs with minimal effort. It can provide part-time respiratory support (especially at night), or expanded support during the day
Invasive ventilation can support your total respiratory requirements however, 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

**Considerations:**

- Avoid people who have symptoms of a cold or flu
- Schedule your annual flu vaccine, and appropriate pneumonia shot
- Discuss with your physician the use of medications to control excessive salivation and frequent ineffective coughing
- Discuss with your respiratory therapist the benefits of breathing techniques to increase ventilation and decrease your work of breathing
- Discuss with your physician appropriate use of respiratory support and airway clearance equipment

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