

Respiratory Homecare for ALS Patients

Loss of the muscles involved in breathing is the gravest problem in advanced ALS.

The respiratory diaphragm, a muscle that lies under the lungs, normally moves up and down when we breathe. As we breathe in, the diaphragm moves down, allowing the lungs to fill with air; as we breathe out, it moves up, letting the lungs expel air.

There are also other muscles, located between the ribs, and in the neck and abdomen, that aid in respiration. All these muscles are weakened or paralyzed in ALS. As the respiratory muscles are losing strength, the person with advanced ALS is also having difficulty coughing and clearing his throat because of weakened abdominal and throat muscles. Normally, the lungs are constantly performing “housecleaning” chores, moving excess mucus and inhaled particles up toward the mouth, to a spot where they can be coughed up.

In the person with ALS, this material doesn’t get coughed up, but falls back down into the lungs, where it can cause respiratory irritation and infection. Weakened swallowing muscles make aspirating (inhaling) food and liquids into the lungs more likely, and these inhaled particles add to the irritation of the respiratory tree. They can also lead to pneumonia or acute choking.

Raising the head of the bed, including during sleep, is a simple but helpful step. This makes both breathing and swallowing easier.

You can help the person you’re caring for rid himself of respiratory irritants by learning how to do an assisted cough. A doctor, nurse or respiratory therapist can show you how to do this maneuver, which involves pressing on the patient’s abdomen as he coughs.

After the assisted cough, you’ll need to use mechanical suction to remove secretions from the mouth. This is also something you can learn from a health professional. You’ll need the suction devices.

As the person with advanced ALS breathes less effectively, the exchange of oxygen and carbon dioxide that’s supposed to occur in the lungs becomes less effective. A person in respiratory distress because of weak muscles can only speak in short phrases. He doesn’t



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seem to have enough air to speak in full sentences. He can't sing or shout. He's unable to cough effectively or sniff hard. His rate of breathing increases, and the breathing appears labored. Sometimes you can see muscles working in the neck or abdomen, trying to compensate for lost function in the diaphragm.

When respiratory distress causes a person to retain excess carbon dioxide, he may have early morning headaches (after sleep), and may be excessively sleepy during the day but unable to sleep well at night. The person may look exhausted and may lose weight rapidly.

At this stage, the doctor will probably begin to discuss respiratory (ventilator) support and ask the client to begin thinking about what kind of support he wants to have.

