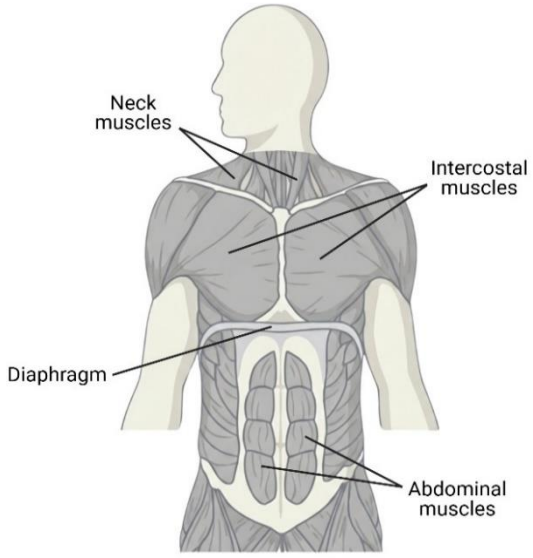
Breathing Issues with Neuromuscular Disease

When you have a neuromuscular disease, it is common to have breathing problems. This occurs because the muscles involved in breathing slowly weaken. These muscles include the diaphragm, intercostals, and abdominal muscles. See the picture and list below that explain where these muscles are and what they do.



Diaphragm
It is the muscle under the lungs. It moves down and shrinks when breathing in (inhaling). It relaxes and moves up when breathing out (exhaling).

Intercostal Muscles
These are muscles between and on top of the ribs. They are used when you breathe in and out.

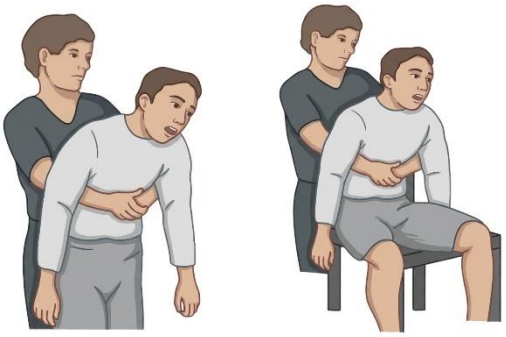
Stomach (Abdominal) Muscles
These are the muscles below your diaphragm. You use them when coughing and when breathing hard. These muscles also help with forced breathing and coughing. Coughing helps to move mucus up and out of our lungs.

Effects of Weakening Muscles
As these muscles weaken, breathing becomes harder. Coughing and swallowing may be harder. Your provider will help you get equipment to make it easier to clear your lungs of mucus and help you breathe more easily.

Swallowing food and choking may also be a problem. Your swallow and speech specialist can teach you ways to get the food you need and reduce your choking risk. Even with this help, it is best to have family members and friends trained to do the Heimlich maneuver.

Heimlich Maneuver for Choking
A choking victim cannot speak or breathe and needs your help right away. **Do not slap the victim's back.** This could make matters worse. Follow these steps to help a choking victim:

1. From behind, wrap your arms around the victim's waist.
2. Make a fist and place the thumb side of your fist against the person's belly, below the ribcage and above the navel.
3. Grasp your fist with your other hand and press into the upper belly with a quick upward thrust. **Do not** squeeze the ribcage.
4. Repeat until the object is coughed or spit out.



The Heimlich can also be done if the person is lying flat as shown in this picture.



Doing the Heimlich on Yourself

When you choke and you can't speak or breathe, you need help right away. Follow these steps to save yourself from choking.

1. Make a fist and place the thumb side of your fist against your upper belly, below the ribcage and above the navel.
2. Grasp your fist with your other hand and press into your upper belly with a quick upward thrust.
3. Repeat until object is coughed or spit out.
4. You can also lean over a fixed horizontal object (table edge, chair, railing). Then press your upper belly against the edge to produce a quick upward thrust.
5. Repeat until object is coughed or spit out.



Cough Assist Machine

The cough assist machine helps to clear mucus from your lungs. When you breathe in, the machine gives you air to help expand your lungs. When you breathe out, the machine pulls the air out of your lungs. This helps make your cough stronger and more effective.



Please see the QR code below for information on the Synclara Cough Assist Machine - Baxter HillRom.

Portable Suction Machine

When you have a neuromuscular disease, it is common to have weakness in tongue muscles. This makes it difficult to move mucus to spit out. A portable suction machine can be used at home to help remove mucus.



BiPAP or Non-Invasive Ventilation (NIV)
As your disease worsens, your breathing can become more difficult. Your doctor will order the use of a type of noninvasive or invasive ventilation. Noninvasive means nothing is inserted into your mouth or throat. This can be done with either a BIPAP device or Non-Invasive Ventilator (NIV). BiPAP or NIV gives you a deeper breath through a mask, which makes your breathing more comfortable. A mask is placed over your nose/mouth and held in place by a head strap.



These devices provide 2 set pressures:

1. Higher pressure when you inhale.
2. Lower pressure when you exhale.

IPAP (Inspiratory Positive Airway Pressure) on inhalation to ensure a good lung volume. This helps reduce CO2 and diminish morning headaches.

EPAP (Expiratory Positive Airway Pressure) stents the airway open for exhaling and alleviating the workload on your respiratory muscles, allowing them to rest.

Why it is Important
Starting therapy early may increase patient adherence, improve quality of life, reduce fatigue and promote better breathing/overall sleep. Research strongly suggests that early intervention extends the user's life.

Device Compliance
Wearing your BiPAP is the best way to capture data on how the machine settings are performing for you and guide your healthcare team in future changes to the device to meet your needs.

Device use has a required minimum of at least 4 hours per night, for majority of nights per month. Your insurance company will conduct a compliance inquiry to ensure compliance is met.

You will be required to complete a follow-up office visit to provide coverage.

Tracheostomy
Sometimes, a more permanent type of ventilation is needed.

A tracheostomy is a surgically created opening in the neck leading directly to the windpipe (trachea). For ALS patients, it is an elective or emergency procedure to bypass the upper airway, manage excess mucus, and connect to a mechanical ventilator when non-invasive masks are no longer effective

Why a Tracheostomy is Needed
As ALS progresses, the muscles responsible for breathing weaken, causing respiratory failure. A tracheostomy may be necessary for the following reasons:

- **Advanced Respiratory Support:** When non-invasive ventilation (like a CPAP or BiPAP mask) can no longer provide adequate breathing support or correct oxygen and carbon dioxide levels.
- **Secretion Management:** ALS can weaken the muscles used to swallow and cough. A tracheostomy allows direct access to the airway to suction out mucus and saliva, preventing choking and lung infections.

- **Airway Protection:** For patients with severe swallowing difficulties, the tracheostomy tube (which often includes a balloon-like cuff) helps prevent food, saliva, or liquids from being aspirated into the lungs.

Choosing a tracheostomy and a mechanical ventilator ("trach and vent") is a major decision, as it is a permanent choice that significantly alters daily living.

- **Full-Time Care:** Patients with a tracheostomy require 24/7 assistance and skilled monitoring to manage the ventilator and prevent blockages.
- **Impact on Speech:** Because the tracheostomy tube sits below the vocal cords and the patient requires continuous positive airflow from the ventilator; it is highly likely that you will lose the ability to speak normally. Alternative communication devices will be needed.
- **Prolonged Survival:** Invasive ventilation can prolong survival, though it does not stop the progression of the underlying ALS disease.

Resources for Decision Making

Deciding on invasive ventilation involves evaluating your personal goals, financial costs, and the impact on family caregivers.

For a deeper look into day-to-day realities and questions to ask your medical team, please review the resources below.

Your ALS Guide Tracheotomy Overview
https://www.youralsguide.com/tracheotomy-and-ventilation.html

I AM ALS Tracheostomy Educational Resources
https://www.iamals.org/wp-content/uploads/2022/04/Tracheostomy-Educational-Resources.pdf

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Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 7/2026. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6450.