

# Respiratory Symptoms & Support

ALS is a neurodegenerative disease that weakens voluntary muscles throughout the body. For the vast majority of people, ALS symptoms first appear in one of the limbs or in the muscles that control speaking and swallowing. Just a small percentage of people notice respiratory symptoms first.

Yet as ALS progresses, it will eventually affect the respiratory system. When ALS weakens the diaphragm (your primary breathing muscle), it becomes harder to fully inhale and exhale. This can lead to common ALS respiratory symptoms such as:



- Trouble breathing while lying down
- Shortness of breath
- General fatigue
- The need for more frequent naps
- Waking with morning headaches
- Feeling groggy or “out of it” in the morning
- Difficulty finishing a sentence without taking a breath
- A weaker cough

Whether or not you are experiencing any respiratory symptoms, it is important to attend an ALS clinic and have your breathing measured regularly. Oftentimes, breathing tests will detect a decline in breathing function before people living with ALS notice any symptoms. Getting respiratory support early can help you sleep better, have more energy, be more comfortable, live longer, and have a better quality of life.

## Respiratory Support

It is important to attend an ALS clinic or see a medical team that can monitor your breathing, recommend respiratory devices, and guide you every step of the way. If attending an ALS clinic is not possible, ask your primary care doctor or neurologist if they can either monitor your respiratory numbers or recommend a respiratory therapist who can do so. Once you qualify for a certain respiratory device, your doctor or neurologist will order the device through a local durable medical equipment (DME) company.

## Respiratory Equipment

Respiratory equipment is therapy for your respiratory system. It can help you sleep better, have more energy, and experience a better quality of life. Studies have shown that using respiratory equipment on a regular basis can help you live longer.

Starting early can help you get used to the devices and begin feeling better sooner. Most respiratory equipment is noninvasive, which means you can take the mask or interface on and off whenever you wish.

## Breathing Exercises for ALS

There are some daily breathing exercises that you can do early in the disease to help you open and expand your lungs, breathe more easily, and have a stronger cough.

“Breath stacking” involves taking a series of short breaths on top of each other without exhaling. After holding your breath for a few seconds, you fully exhale all at once. With expiratory and inspiratory muscle training, you use a small, handheld device to inhale and exhale against a resistance level that is set and adjusted according to your breathing test measurements. Other helpful breathing techniques include huffing and deep diaphragmatic breathing.

## Improving Your Sleep

Getting a good night’s sleep is important for your health, well-being, and energy level. If you are finding it hard to get a solid night’s sleep, or are finding it harder to breathe when lying down, it may help to prop yourself up with pillows or a bed wedge. If you are still not getting the rest you need, it may be time to get a bilevel (BiPAP) machine or use a portable ventilator in bilevel mode to assist you with breathing while sleeping. This should improve your quality of sleep and help you feel more rested when you wake up.

## Shortness of Breath

If you are experiencing shortness of breath, it is likely the result of a weakened diaphragm muscle. This makes it harder to expand the lungs enough to fully receive oxygen and fully exhale carbon dioxide. Typically, a bilevel machine or a portable ventilator will help. Most people living with ALS do not need supplemental oxygen. The exception is when your oxygen levels drop below normal levels, which is usually from an underlying lung condition such as COPD or emphysema.

### Get Local Support



**ALS United North Carolina**  
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