

Facts about Breathing Support: What you should know

This guide is for those whose advanced illness is getting worse despite treatment. It can help you decide what type of breathing support you may need soon, or in the future. Your doctor or care provider can explain risks, benefits, and options specific to your condition.

Why might I need breathing support?

The time may come when simply breathing in and out is hard work. Your stress and symptoms could prompt your healthcare team to recommend breathing support from a machine called a **ventilator**. It is best to consider this treatment option before there is a crisis.

In some cases, breathing support can help you live well for many years. In other cases, breathing support may lessen discomfort but not help you live much longer. In these cases, breathing support may extend the dying process without helping improve health, function, or ability to resume a normal routine.



When might I need to consider breathing support?

You may need breathing support if:

- Your breathing muscles are being weakened by a progressive disease.
- A well-managed chronic condition gets worse, despite the best treatment, and causes breathing failure. This can occur in severe chronic obstructive pulmonary disease (COPD) or congestive heart failure (CHF).
- Your immune system isn't strong enough to protect you from pneumonia or other lung infections.
- An advanced stage of cancer or another disease leaves you with few treatment options. The side effects may be more severe than you can withstand.
- You are actively dying from disease or from damage to your body that cannot be repaired.

In some cases, breathing support might not correct the problem that threatens your life. Chances of your return to a normal routine could be slim to none. Some forms of breathing support might ease discomfort and other symptoms caused by breathing failure.

How and when should I decide?

Choosing to use or not use a machine to help you breathe can be a challenge. It may take time to think about your goals, values, and beliefs. To help you make a decision about whether breathing support is the right choice for you, talk with:

- Your healthcare providers
- Your family or those closest to you
- Other people with a condition like yours who use machine-aided breathing
- A faith or community leader who has helped others face choices like yours

It is never too soon to think about how breathing support will or will not meet your goals for living well.

Types of breathing support

A **ventilator** is a machine that supports breathing. It pushes air into your lungs when your chest muscles cannot rise and fall on their own.

There are 2 main types of ventilation or machine-aided breathing:

During **invasive ventilation**, air is moved through either a:

- Long, thin tube through your mouth, down your throat
- Tube in your neck and trachea (windpipe), placed by a surgeon. Long-term invasive ventilation always requires a tracheostomy [tray-kee-OS-toh-mee].

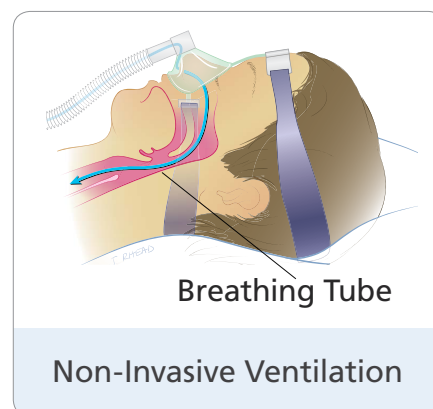
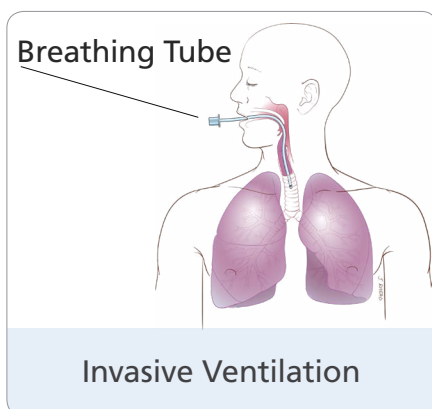
During **non-invasive ventilation**, air is moved through:

- A mask that covers your nose and mouth
- Nasal pillows that fit inside your nostrils
- A mouthpiece

Many people who use this method need it only at night or for part of the day.

Discuss these methods with your healthcare team long before your breathing might fail in late stages of disease or chronic illness.

Note: If you have a neuromuscular disease, there may be other breathing support options, although none will cure you. Please talk to a specialist to learn more about these options.



When does it make sense to use breathing support?

Machine-aided breathing can help you live well with illness or disability in these situations:

- For a short time while recovering from surgery, sudden illness, or severe injury.
- For a longer time, if your condition affects breathing but not other body systems.
- For a long-term medical condition that is somewhat stable or changing slowly. These include but are not limited to:
 - **Neuromuscular disorders** such as muscular dystrophies or amyotrophic lateral sclerosis (ALS, otherwise known as “Lou Gehrig’s disease”)
 - **Scoliosis** or other skeletal disorders
 - **Sleep-disordered breathing**

A breathing machine can also help lessen uncomfortable symptoms from heart failure or chronic lung disease, although it will not resolve the reason for your breathing problems.

A portable breathing machine may allow you to leave your home or care facility, sometimes for up to 24 hours. This is more likely if you are in a wheelchair and have trained caregivers to help.

Machine-aided breathing cannot help you achieve your goals for living well if:

- Your body is shutting down from long-term health problems.
- Death is likely in the near future.
- Your mind is too impaired by Alzheimer’s, another disease, or trauma to allow breathing support. You may need to be restrained to use a mask, nasal pillows, mouthpiece, or breathing tube.

What are the side effects of machine-aided breathing?

Machine-aided breathing comes with some side effects. These could happen soon after you try breathing support:

- The face mask or tube in your nose or throat could cause discomfort.
- You may have trouble swallowing or talking.
- When used in a health facility, sedation may be required for invasive ventilation. This would limit your ability to engage with family and friends.

After days or weeks of invasive ventilation, you may need surgery to create a stable airway (tracheostomy). You may be able to talk and eat again, but:

- Increased secretions (mucus, fluids) and infections may require more frequent hospital stays.
- Your need for skilled care will increase.

You should consider who could provide this care if you cannot learn to do it for yourself. Friends and family might not be able to care for you. You may lack the funds to pay for in-home skilled care. Options for long-term living must be addressed. Health insurance and government-funded home care policies will affect your choices. You may have to move to a nursing home or ventilator care facility.

What could happen if I decide not to try breathing support?

If your breathing starts to fail and you have decided not to have breathing support, you could experience uncomfortable symptoms. These symptoms are caused by the increased stress of breathing. You may feel anxious as less air gets in and out of your lungs. If you decide not to have breathing support and your main goal is comfort, your symptoms can be relieved in other ways.

In the final stages of breathing failure, you may become drowsy and, at some point, unconscious. Talk about any fears you may have with your doctor so you can get the best symptom treatment. Healthcare teams that are trained to manage symptoms can be very helpful and should be involved. If you decide not to start breathing support but find that you feel differently later, you may change your decision.

What if I decide to use long-term breathing support?

You and your family will receive education and support. Machine-aided breathing at home will almost always require help from family, friends, or paid staff. You are likely to need care 24 hours a day, particularly if you have a tracheostomy. Insurance may cover some nursing or respiratory care, though often for only a limited time.

If you do not have enough help to stay in your home, you will need to be in a special facility. A tracheostomy, ventilator, and tubing require frequent suction and cleaning by yourself, trained family, home care workers, or facility staff.

Once I choose breathing support, can I change my mind?

If you decide to try breathing support, you can always change your mind. Your choice to start or stop ventilation of either type can be reviewed at any time. Making family, friends, and loved ones aware of your choices and concerns is crucial. When you can no longer communicate with your care team, those closest to you must be prepared to speak and act on your behalf.

Before you decide either way, take all the time you need to reflect on what matters to you. Discuss these issues with those closest to you. Ask health professionals about the full range of machine-aided breathing options. No matter what choices you make, be sure to:

- Tell your doctor.
- Tell your healthcare agent so they can decide on your behalf when you can no longer speak for yourself.
- Tell others close to you.
- Complete an advance directive.

For more information on living with long-term breathing support, visit the **International Ventilator Users Network** website at: ventnews.org.

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