

The background of the page features a soft-focus photograph of several starfish resting on a sandy beach. The starfish are in various orientations and sizes, with some appearing more prominent than others. The overall tone is light and natural.

Breathing Support Facts:

What you should know

This guide is for those whose advanced illness is getting worse in spite of treatment. The time may come when simply breathing in and out is hard work. Your stress and symptoms could prompt your healthcare team to suggest you get breathing support from a machine called a ventilator. It is better 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 lengthen life very much. In these cases, breathing support may extend the dying process without helping improve health, function, or ability to resume a normal routine. This guide can help you decide whether you want to try using machine-aided breathing soon or in the future. Your doctor or care provider can explain risks, benefits, and options suited to your condition.

What situations and conditions may prompt this discussion?

- 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 is too frail to protect you from pneumonia or other lung infections.
- Advanced stages of cancer or any other disease leaves you with few treatment options. Their side effects may be more severe than you can withstand.
- You are actively dying from disease or 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 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 learn more before you decide:

- Ask your healthcare providers.
- Talk with loved ones and family.
- Ask other people with a condition like yours who use machine-aided breathing.
- Speak to a faith community leader who has helped others face choices like yours.

This guide provides background needed for these conversations. **It is never too soon** to think about how breathing support will or will not meet your goals for living well. It helps to decide before you are in a crisis.

What is a ventilator?

A ventilator is a machine that supports breathing. It pushes air into your lungs when chest muscles cannot rise and fall. There are two main types of ventilation (machine-aided breathing).

Invasive ventilation - Air moves through one of these:

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

Non-invasive ventilation - Air moves through one of these:

- 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 health care team. Do this 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 options although none will cure you. Please talk to a specialist in your condition 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 if:

- You use it short-term while you recover from surgery, sudden illness, or severe injury.
- You use it long-term when your condition affects breathing but not other body systems.
- You use it long-term for a 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 be used to help lessen uncomfortable symptoms from heart failure or chronic lung disease, though the cause of those symptoms cannot be removed by the machine that aids your breathing.

Many breathing machines can be used in the community, even during the day with up to 24 hours use, particularly if a person is a wheelchair user and has trained caregivers. You may be able to leave your home or care facility with a portable system.

A ventilator 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 or other disease or trauma to allow breathing support. You may need to be restrained to use a mask, nasal pillows, mouthpiece, or breathing tube.

Side effects of machine-aided breathing

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, surgery may be required to create a stable airway (tracheostomy). If you have a tracheostomy:

- You may be able to talk and eat again.
- More secretions and infections may require hospital stays.
- Your skilled care needs will increase.

You must think about 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. This is caused by the increasing 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 the final stages of breathing failure, you may become drowsy and at some point unconscious. Talk about your fears with your doctor so you get the best symptom treatment. Health care teams 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 and/or respiratory care, though often for only a limited time. If you do not have enough help to stay in your home, you would 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.

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. 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 those you choose to decide on your behalf when you no longer can.
- Tell others close to you.
- Complete an advance directive.

For more information on living with long-term breathing support, visit

The International Ventilators Users Network website:

<http://www.ventusers.org/>.



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