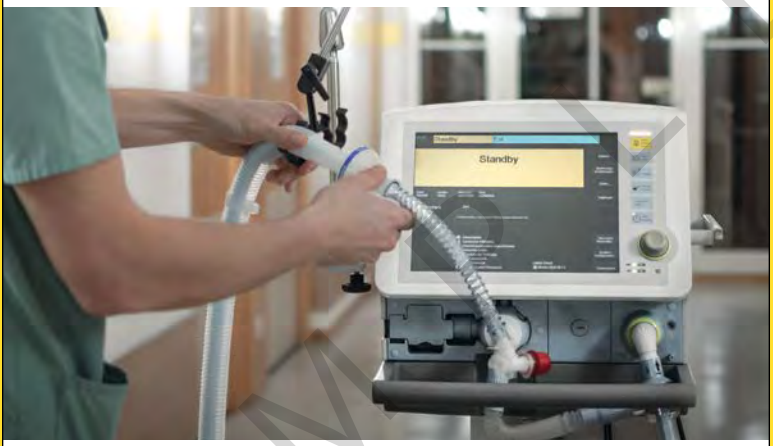
Ventilator Use



A GUIDE FOR SERIOUSLY ILL PATIENTS
AND THEIR FAMILIES

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Introduction

When you or someone you know is seriously ill, you may be faced with very hard choices. There may be many treatment decisions to make. It can be a lot of information to take in all at once. Ventilator use can be an especially tough decision to make for someone who is seriously ill or injured.

Very sick patients may reach a point when they can't breathe on their own. Other patients may have a sudden event that causes breathing problems. Some patients might already be on a ventilator. These patients or their families will need to know what to expect.

You may be a patient, a caregiver, or you may know someone who is seriously ill. This booklet will help you understand what a ventilator is. It can help prepare you for what is ahead.

Let us know if you have any questions. We are your care team, and we're here to support you during this difficult time.

"What really makes these decisions 'hard choices' has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual....These are decisions of the heart, not just the head."

— Hank Dunn, MDiv, from *Hard Choices for Loving People*

What Is a Ventilator?

When people say someone is "on life support" or "hooked up to a machine" they probably mean a ventilator. Healthcare professionals call it "mechanical ventilation."

Ventilators are breathing machines. They push air into the lungs, carry oxygen to the body, and take carbon dioxide out. Other equipment and tests may be used to track the patient's pulse, breathing, and oxygen levels.

Basic parts of a ventilator:

- Control panel (screen/dials to control air flow and track the patient's oxygen levels)
- Gas/oxygen tank
- Air compressor (a machine to pressurize the gas/oxygen)
- Humidifier (a machine to warm and moisturize the gas for the patient)
- Set of tubes and valves (parts that connect the machine to the gas tank)
- A "patient circuit" (parts that connect the machine to the patient, with a mask or a tube)

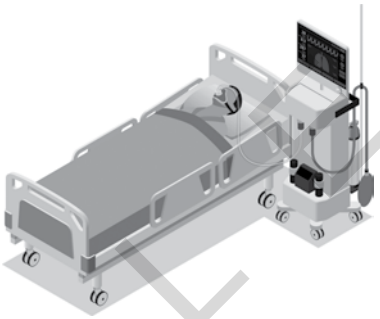
The ventilator your care team uses may look different, but most share the same basic parts.

There are many different "modes" of mechanical ventilation, or ways the machine can help a patient breathe. The doctor or respiratory therapist (a healthcare professional who specializes in helping patients with breathing problems) will choose which mode to use based on the patient's needs.

Some modes let the patient do some of the breathing. Others do all of the breathing for the patient. The care team can adjust the ventilator as needed.

What Is it Like to Be on a Ventilator?

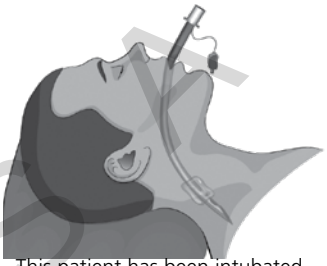
Some people do well on a ventilator. But many people find it uncomfortable. Patients on a ventilator will have trouble talking or will not be able to speak at all. Most patients also cannot eat while on a ventilator.



If the patient has a face mask, the nose, mouth, and lips may become very dry. The mask can sometimes cause sores on the face. Some patients may feel claustrophobic, or closed in.

Endotracheal intubation (breathing tubes)

Some patients must be "intubated" to be connected to the breathing machine. A tube is inserted into the throat and down the windpipe. Some tubes are inserted into a hole in the patient's neck with surgery. These are called tracheostomy or "trach" (rhymes with "rake") tubes.



This patient has been intubated.

Patients with breathing tubes might "fight" the ventilator until they adjust to it. They may try to breathe out when the machine pushes air in. A doctor can order medicine to relax the patient.

Patients may lose their voice or have a sore throat after the tube is removed. While this can be unpleasant, it is usually not a problem with short-term ventilator use.

When Should a Ventilator Be Used?

Ventilators are used when a patient needs heavy anesthesia (medicine to put them in a sleep-like state), such as for surgery. This kind of ventilator use for otherwise healthy patients is often successful.

A doctor might also order a ventilator if a patient can't breathe well or can't breathe on their own at all. Breathing problems can be caused by damage to the lungs, brain, or spinal cord. Lung damage can come from:

- COPD (chronic obstructive pulmonary disease)
- Asthma
- Lung cancer
- Cystic fibrosis
- Muscular dystrophy
- ALS (Lou Gehrig's disease)
- Other chronic diseases
- Lung infection/pneumonia
- Heart attack
- Stroke
- Sudden accident or injury

Ventilators do not cure the disease that caused breathing problems. They do not fix lung damage. Most often ventilators are used for a set amount of time. Some patients with chronic (long-term) illness, like muscular dystrophy or ALS, may benefit from longer use.

Weaning patients off of a ventilator

Often the goal is to take the patient off of the ventilator as soon as possible. Patients who are strong enough are weaned off of the machine. The care team slowly adjusts the ventilator settings until the patient is breathing mostly on their own.

The care team may also test the patient's breathing. If the patient breathes with little support for 2 hours, they can likely be taken off the ventilator. If the patient doesn't pass the test, the care team will re-adjust the settings and try again later.

Risks of Ventilator Use

There is no doubt that ventilators save many lives. Short-term use of a ventilator (like for surgery) is common and normally safe. Using a ventilator for more than a day can put a patient at risk for:

- Increased use of pain medicine or sedatives (drugs to make the patient sleepy)
- Restraints (to keep the patient from pulling out the tube)
- Feeding tube use (ask us about the benefits and risks of feeding tubes in your case)
- Toxic levels of oxygen
- Sinus infection
- Lung damage
- Pneumothorax (when air leaks into the chest cavity and causes the lungs to collapse)
- Lung infection/pneumonia

The risks of ventilator use are greater for elderly, weak/frail, or seriously ill patients (see page 8). These patients may not get strong enough to be taken off the ventilator. Careful thought should go into ventilator use for these patients.

Ventilators and Pneumonia

Pneumonia ("nuh-**mow**-nyah") is a very common and serious lung infection caused by germs—virus, bacteria, or fungus—that enter the lungs. The infection fills the air sacs in the lungs with fluid and makes it hard to breathe. Ventilators are often used in very serious cases.

Anyone can get pneumonia. Older people, young children, and those who already have health problems are more at risk for serious illness from pneumonia. Serious cases can lead to a hospital stay or even death.

A person's chance of getting better is based on their age, overall health, and the cause of pneumonia.

Common symptoms of pneumonia include:

- Cough
- Sharp chest pain
- Fever or chills
- Shortness of breath
- Trouble breathing
- Feeling weak or tired
- Stomach problems
- Confusion

Pneumonia can also be caused by long-term ventilator use. Germs can get into the lungs from the air tube. This is known as ventilator-associated pneumonia, or VAP.

A ventilator can help pneumonia patients breathe until they get better. But it will not cure pneumonia.

Treatment for pneumonia depends on the cause. If it was caused by bacteria, the doctor will likely prescribe an antibiotic. If it was caused by a virus, rest, drinking plenty of fluids, and taking drugs to reduce pain, fever, or other symptoms may help.

Ventilators and COVID-19

In late 2019, the severe lung disease called COVID-19 began to spread quickly around the world. Some healthcare systems became overrun. Hospitals ran short on medicine, supplies, and equipment used to support COVID-19 patients—including ventilators.

COVID-19 is caused by a virus. Scientists call it the "novel" (new) coronavirus. It is not the same as the common coronaviruses that cause mild illness, like a cold.

Anyone can get COVID-19. Many people who get it have a mild case and get better. Older people and those with other health issues are more at risk to become seriously ill. But even people who have no other health issues can be at risk.

Serious cases of COVID-19 can cause breathing problems, pneumonia, major organ failure, and death.

The main symptoms of COVID-19 include:

- Cough
- Fever
- Shortness of breath

Ventilators can play a major role in keeping very seriously ill COVID-19 patients alive. It is important to avoid catching and passing on this disease. This will help keep people who are most at risk safe and ensure hospitals have enough ventilators for patients who need them.

Visit **www.cdc.gov/coronavirus** for more information about the disease and how to slow the spread.

Ventilators for Seriously Ill Patients

When a seriously ill patient has trouble breathing, it can be hard to watch. Families might feel powerless and look for ways to help. Putting the patient on a breathing machine can make it feel like they are taking action.

But ventilator use for certain seriously ill patients might not be recommended. A patient may be considered seriously ill if they have:

- A high risk of death (though cure may be possible)
- A low quality of life; they are not able to do daily tasks on their own or do things they enjoy
- High burdens from pain, other symptoms, and treatments
- A caregiver under a lot of stress from caregiving tasks

Things to keep in mind:

- Medical experts say ventilators should only be used long term when there is a chance the illness that caused the breathing problems can be cured.
- If the patient is not healthy enough to get better, they may be on a ventilator for the rest of their life. Elderly patients, weak/frail patients, or patients with more than one health issue are at the most risk for this.
- Many people say they do not want to be hooked up to machines at the end of life.
- It may be harder emotionally to remove ventilator support than it is to not start it at all.

If there is a choice, it might be most compassionate to let the illness run its natural course. The care team will keep the patient as comfortable as possible, no matter what. Talk to us about the patient's condition. We can give you more information to help guide your decision.

Time-limited trials

In certain cases, the doctor may allow a time-limited trial. The patient is put on a ventilator and reassessed at a later date. The care team may also try to wean the patient from the machine (see page 4) to see if breathing has improved.

If the patient does not improve or gets worse, the doctor will likely suggest taking the patient off the ventilator.

Choosing for someone else:

- **Keep the patient's interests in mind.** Always ask, *"What would the patient want? What would they think about the condition they're in?"*
- If the person has a living will or advance directive, follow those instructions.
- If they did not leave instructions, try to think back to conversations you had. Knowing what you know about the person, what would they decide?
- If you think it might be helpful, discuss this with your family or the care team.
- **Be gentle with yourself.** This is a heavy burden to bear. Do the best you can with the information you have.

What if we didn't have a choice?

Sometimes there may not be a choice in a medical emergency. The doctor may automatically order a ventilator if they do not have clear instructions from the patient or family.

In other cases, even if the patient or family wants one, a ventilator could still be withheld or withdrawn if the doctor believes it won't help—or will harm—the patient.

In any case, it is important to talk about healthcare wishes as early and as often as possible.

Withholding or Withdrawing

A seriously ill patient may reach a point when they won't be able to breathe on their own again. The doctor might recommend withholding (not starting) ventilation. For these patients who are already on a ventilator, the doctor may recommend withdrawing (stopping) ventilation.

This can be an especially hard decision. It may feel like withholding or withdrawing a ventilator is causing the person's death. You might feel responsible or guilty. **It may help to remember it is *the disease* that causes death, not the decision about ventilator use.**

Some people worry that withholding or withdrawing the ventilator will mean the patient will struggle or be in pain for the last moments of life. But the care team will work to make the patient comfortable. Sedatives or pain medicine may help calm the patient. These medicines do not hasten death.

"By removing the ventilator,
we are allowing a natural death to occur
that would have happened earlier if the
machine had never been started."

— Hank Dunn, MDiv, from *Hard Choices for Loving People*

Withdrawing a Ventilator at the End of Life

The doctor does not believe the patient will get better. The incredibly difficult decision has been made to take the patient off the ventilator. What next? Doctors, nurses, respiratory therapists, chaplains, and other staff as needed will be available. The care team's goal is to make the process as gentle and peaceful as possible.

What to expect:

- The care team will discuss the next steps with the family and answer questions.
- If possible, the care team will wait for family to arrive. In some urgent cases, they may not be able to wait. Be gentle with yourself if you cannot be there. Know that the person will not be alone and they will be cared for.
- The care team will stop all non-comfort measures, turn off alarms, and try to make the space as calm as possible.
- Feeding tubes may be kept in place or removed, depending on the situation.
- Pain medicine and sedatives can be adjusted to make sure the patient is comfortable.
- Space will be made at the bedside for loved ones who can be there. If loved ones are not able to be there, a nurse, chaplain, or other care team member may be present to provide support.
- The care team will check the patient again for pain or distress just before removing the ventilator. They will adjust medications if needed.
- The ventilator is turned off and the tube is gently removed.

As death approaches:

- Most very seriously ill patients live a short time after the ventilator is removed. The amount of time varies, but it is usually about an hour or less.
- During this time, saliva may gather in the patient's throat and cause a rattling sound. It may be alarming to hear, but it does not cause the patient discomfort.
- There may be other changes as death nears. Talk to the care team if you are concerned. We can give you more information on what to expect. We will continue to keep the patient as comfortable as possible.
- Even if a patient seems like they're sleeping, they may be able to hear what is happening around them. If you are by the bedside, only say things you would say if the person were awake.
- You may want to spend this time expressing your love, saying thank you, saying goodbye, holding their hand, or simply being present.

*"Please forgive me. I forgive you. Thank you. I love you...*These four short sentences carry the core wisdom of what people who are dying have taught me about what matters most in life."

— Ira Byock, MD, from *The Four Things That Matter Most*

Care for Family and Friends

Deciding to withhold or withdraw ventilation is one of the hardest choices you may ever make. It is normal to feel sad, angry, guilty, overwhelmed, regretful, or confused. You may also feel shocked, numb, or even relieved.

It is also normal to have feelings of grief, even while the person is still alive. This is known as "anticipatory grief." It is grief that comes before an expected loss.

You are allowed to feel the way you feel. All of your feelings are valid. If you need support, you are not alone.

What you can do:

- Take care of yourself. Get rest, eat a healthy diet, and drink plenty of water. Try to stick to an exercise routine or go for a walk each day.
- Reach out for support. Talk with a trusted family member, friend, counselor, or clergy member about what you are feeling. The care team may have a chaplain who can provide extra emotional support. There may also be support groups in your community and online.
- If the choice is made to withhold or withdraw life support, it may help to remember that your courage freed the patient from pain and suffering.
- Take each day one step at a time. **Contact us if you or your loved ones need support. We are here for you.**

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