

Ventilator Decision Aid

What is a ventilator?

A ventilator (also called a breathing machine) does the work for the lungs when someone is unable to breathe on their own.

What happens when someone is attached to a ventilator? How is it done?

- A tube is placed through the mouth or nose down into the person's windpipe (trachea).
- A machine (the ventilator) pushes air through a tube into the lungs.
- Medicines are often given in an IV (intravenous) line to make a person sleepy so they feel less pain or discomfort.

When do people need a ventilator?

It may be needed for people who cannot breathe normally on their own. Breathing problems may be short-term (temporary) or long-term (permanent).

It is standard medical practice to use a ventilator to treat people who cannot breathe on their own, *unless* the person has chosen not to have it.

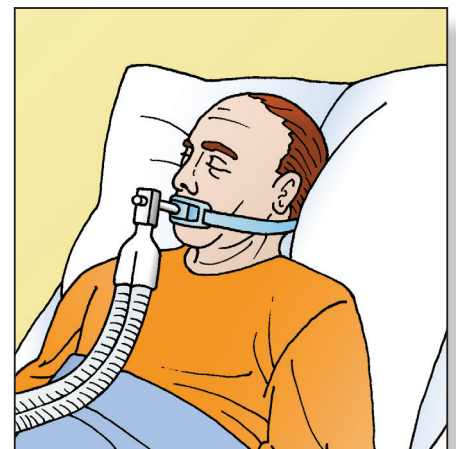
Reasons for short-term ventilator use may include:

- Surgery with anesthesia (medicine that makes you sleep).
- A sudden, serious illness, or a severe injury.
- Problems caused by serious lung disease, such as COPD (chronic obstructive pulmonary disease), emphysema, asthma, or pneumonia.
- Fluid in the lungs from heart problems or swelling.

Reasons for long-term ventilator use may include:

- Extreme weakness, when the breathing muscles do not work well.
- Being in a coma, when the brain and nerves that control breathing do not work normally.
- Diseases of the muscles or nerves, injury to the spinal cord, or severe lung damage.

Some people might permanently lose the ability to breathe on their own.



Who should use this guide?

This decision aid is for people with serious illness. It can be used to support medical decision-making and conversations about **treatment with a ventilator**.

Note: This document does not discuss options for non-invasive breathing support. That means ways to help you breathe without using a ventilator.

How might using a ventilator help a person?

- In sudden illness, a ventilator might help to keep a person alive while the medical team treats them.
- A ventilator works to support breathing and get oxygen to the body's organs.
- A ventilator can support breathing during surgery or other serious medical procedures.
- A ventilator can allow some people to improve after a trauma or spinal cord injury, and to live longer.



How might using a ventilator cause harm?

- People on a ventilator can get lung infections that may be hard to treat.
- The ventilator can damage the lungs and make breathing muscles weak.
- People on a ventilator in the hospital often cannot speak or swallow. These may be long-lasting side effects.
- Some people become confused or scared while on a ventilator.

Does using a ventilator help people to get better?

It depends on the type of medical problems they have and why they need a ventilator.

Who is most likely to be helped by being on a ventilator?

- People who were mostly healthy before the illness or injury and have the physical strength to recover.
- Those who only need a ventilator for a short time (days or a week or two).
- People who feel they can have an acceptable quality of life with a ventilator. For example, a younger patient with a serious spinal injury, or a person with a disability.

Who is less likely to be helped by being on a ventilator?

- People who are seriously ill from heart, lung, liver, or kidney failure.
 - Those who have a terminal illness, such as advanced cancer or advanced dementia.
 - People who are older, weaker, or very frail.
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What is it like being on a ventilator?

Most people on a ventilator can't talk, drink, or eat, and are usually not awake.

People on a ventilator are often given medication to keep them relaxed. When they are awake, some people may feel uncomfortable or anxious. The medical team is careful to treat these symptoms.

Once someone is on a ventilator, can they come off?

Yes, people can come off the ventilator when they can breathe on their own or any time they decide to stop using it, such as when their treatment plan changes. People who are unsure about a ventilator may want to try it for a short time (a trial period) to see if it helps.

What happens if someone needs a ventilator for a long time?

- After about two (2) weeks, the medical team will make the breathing tube more secure and comfortable. A hole for the breathing tube is made by surgery in the neck and windpipe (trachea).
 - A person who needs long-term ventilator support might need to move to a different hospital. It may be a long-term acute care hospital (LTAC), a skilled nursing facility (nursing home or SNF), or they may require special in-home care.
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What happens to people who decide NOT to try a ventilator?

They can still get other treatments.

People who decide ahead of time that they don't want to try a ventilator can still get other treatments they might need. This may include surgery, time in the intensive care unit, or other treatments and medications. Help with pain is always available.

- Breathing may be supported in other ways.
 - » Ask about options for non-invasive breathing support.
- Medicines can be given to help with shortness of breath.
- People who do not want to be on a ventilator should also talk to their doctor about CPR because people who get CPR often need a ventilator for a period of time.



They may not be able to prolong life.

If a ventilator is needed for breathing and is not used, then death may not be delayed.

How do people decide whether or not to try a ventilator?

They talk with their doctor about how a ventilator might affect their health or quality of life. They think about the benefits or possible harms of a ventilator to see if it is right for them.

It is important to talk with your doctors and medical team about:

- How a ventilator might help you to reach your goals, such as getting back to a certain level of health or ability.
 - Whether the ventilator might be needed for a short time or a long time.
 - What kind of harms the ventilator might cause.
 - How long you might live with a ventilator or without it.
 - What life might be like during and after using a ventilator.
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Who chooses to try a ventilator?

- People who expect to get better and live well after short-term ventilation.
- People who feel they have an acceptable quality of life with long-term ventilation.
- Some people whose main goal is to live as long as possible may choose to try a ventilator, even if it may cause other possibly serious medical problems.

Who chooses NOT to try a ventilator?

Some people with a serious or life-limiting illness may choose not to try a ventilator because they may want to:

- Avoid being in a hospital or other facility with little benefit.
- Avoid being indefinitely hooked up to tubes and machines with little benefit.
- Avoid possible harms from being on a ventilator with little benefit.
- Avoid delaying natural death while not hastening it.

What feels right for you?

When thinking about yourself and your choices, it may help to talk with:

- Anyone who might make medical decisions for you in the future.
- Any person for whom *you* are the medical decision-maker.
- Your doctors and medical team.
- Family or friends.
- Your spiritual or faith leaders.
- Others who have chosen to use a ventilator in similar situations.

If you do not want a ventilator, ask for special medical orders to be written by your medical provider.

Making Your Decisions Known

- Tell your family, close friends, and your doctor about your decision.
- Create an Advance Directive* and choose someone to speak for you when you cannot speak for yourself.
- Discuss advance care planning with your medical provider and whether your decision should be recorded in a special medical order. (Learn more at POLST.org.)
- Give copies of these forms to your family, to your doctors, and to your hospitals.
- Keep important documents in an easy-to-find place.

*Advance health care directive forms are available at WholePerson.care, CoalitionCCC.org or from your healthcare provider.



Caring for the Whole Person is a statewide initiative of the California Bishops and Catholic healthcare systems designed to provide resources and tools to ensure that seriously ill parishioners and patients are loved and supported; can openly talk to their spiritual leaders, clinicians and family members about their wishes at end of life; and have access to quality palliative care. This decision aid was developed in partnership with the Coalition for Compassionate Care of California. For additional copies or more information, contact info@wholeperson.care. Additional resources are available online at WholePerson.care and CoalitionCCC.org.