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.
- A ventilator is often used while a person is asleep (under anesthesia) for surgery.

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 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).

Reasons for short-term ventilator use may include:

- Surgery with anesthesia (when you are put to sleep).
- Sudden, severe illness, or injury.
- Serious lung disease such as COPD, 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 may cause some people to permanently lose the ability to breathe on their own.

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



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 noninvasive breathing support. That means ways to help you breath without using a ventilator.

How might using a ventilator help?

- In sudden illness, a ventilator can try 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 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, and these may be long-lasting side effects.
- Some people become confused or scared while on a ventilator in a hospital or ICU.

Does a ventilator work to help people to get better?

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

Who is most likely to be helped from 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 using a ventilator?

- People who have advanced or terminal illness 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.

What is it like being on a ventilator in a hospital or ICU?

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

Often, people on a ventilator are 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 may want to try a ventilator for a short period (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. During surgery, a hole for the breathing tube is made 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) or a skilled nursing facility (nursing home), or they may require special in-home care.

What happens for people who decide NOT to try a ventilator?

They can still get other treatments. Deciding ahead of time that you don't want to try a ventilator does not mean you can't get other treatments you might need. This may include surgery or time in the intensive care unit. 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 medical team about CPR because people who get CPR often need a ventilator, as well, 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 medical team about how a ventilator might help them to reach important health goals. They think about the benefits or possible harms to see if it is right for them.

Talk with your doctors and medical team about:

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

Who chooses to try a ventilator?

- Some people who are able to get better or are expected to live well and to have an acceptable quality of life.
- Some people whose main goal is to live as long as possible, even if it may cause other medical problems.

Who chooses NOT to try a ventilator?

Some people who want to avoid:

- Being in a hospital or other facility.
- Being hooked up to machines.
- The possible harms from being on a ventilator.

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 you might be making medical decisions for.
- Your doctors and medical team.
- Family or friends.
- Your spiritual or faith leaders.
- Others who have chosen to use a ventilator in a similar situation.

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

Make Your Decisions Known

- Tell your family, close friends, and your doctor about your decision.
- Create an Advance Directive* and assign someone to speak for you when you cannot speak for yourself.
- Talk with your medical provider about 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 CoalitionCCC.org or from your healthcare provider.



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References, copies, and additional aids are available online at CoalitionCCC.org or by email to info@CoalitionCCC.org.

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