CPR facts - what you should know

This guide provides information about CPR (cardiopulmonary resuscitation) and how well it may work for you. You will need to talk with your doctors about what you might expect. CPR has side effects that you should know about before you make a decision. Age and health make a difference. The doctor who knows you best can help you make a decision.

What is CPR?

CPR is an emergency procedure to try to restart your heart and breathing if they stop. CPR can include any or all of the following:

- Pressing on your chest.
- Mouth-to-mouth breathing or a tube to help get oxygen into your body.
- Electrical shock and medicines.

Will CPR work for you?

Talk with your doctor about how well CPR would work for you. Some things to consider:

- CPR works best if you are healthy and CPR is started immediately after your heart and breathing stops.
- CPR is less likely to be successful if you are older, weak or living in a nursing facility.
- CPR does not fix or improve the reason that caused a person's heart and breathing to stop.

What can happen after CPR?

- If you receive CPR outside of the hospital, it requires transfer to a hospital to receive ventilator (breathing) support and care in an ICU (intensive care unit).
- If you survive, you may return to your current health, or you may have a decline in your physical or mental function.

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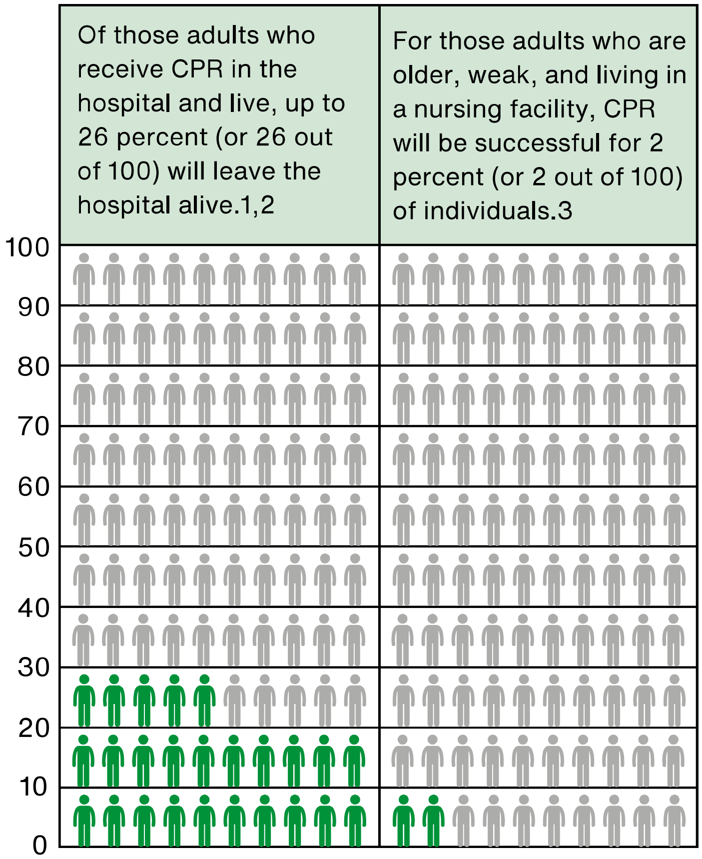
Making a decision about CPR.

Talk with your doctor about what results you might expect with CPR. If you do not want to try CPR, talk to your doctor about how to document your decision by creating a medical order. Whatever you decide, you will always be offered appropriate care and make other health care decisions. Tell your doctor and patient advocate about your decision.

The success of CPR

By "success," we mean living through CPR and being able to leave the hospital.



Of those adults who receive CPR in the hospital and live, up to 26 percent (or 26 out of 100) will leave the hospital alive.1,2

For those adults who are older, weak, and living in a nursing facility, CPR will be successful for 2 percent (or 2 out of 100) of individuals.3

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Breathing Support Facts - what you should know

This guide is for those whose advanced illness is getting worse despite treatment. The time may come when simply breathing in and out is hard work. Your stress and symptoms could prompt your health care 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), amyotrophic lateral sclerosis (ALS), otherwise known as Lou Gehrig's disease, 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 health care 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.

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More information on the next page.

Breathing Support Facts - what you should know

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.
- You use it long-term for a medical condition that is somewhat stable or changing. These include but are not limited to:
  - Neuromuscular disorders such as muscular dystrophies or ALS.
  - 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.

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). You may be able to talk and eat again, but:

- More secretions and infections may require hospital stays.
- Your skilled care needs will increase.

More information on the next page.

Breathing Support Facts - what you should know

You must think about who could provide this care if you cannot learn to do it for yourself. Friend 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 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.

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

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 you, trained family, home care workers or facility team member. 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. Having 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.

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Long-term tube feeding facts - what you should know

This guide is for those whose advanced illness is getting worse despite treatment. It is meant to help you decide whether you want long-term tube feeding as part of your care. Talk to you doctor or care provider mabout risks and benefits that apply in your case.

What is tube-feeding?

A gentle pump or large syringe is used to put liquid food into the body through a tube. The most common pathways are:

- A tube through your nose into your stomach (for short term use) known as an NG-tube.

Or

- A tube put through the skin into your stomach (long-term use) known as a PEG-tube.

Does tube-feeding work?

Tube feeding can help you live well with illness or disability. It works best if:

- You are healthy enough, even with your illness or disability, to benefit from feeding.
- Your illness or disability makes it hard to swallow or take in enough nutrition.

Tube feeing may not help you live well if:

- Your body is failing despite treatment and death is likely in the near future.

Long-term tube feeding helps many people live longer lives and in better health.

It may be the right choice for you if:

- You cannot swallow safely because you have a head, neck or throat cancer.
- Muscles in your throat are weakened by:
    - Amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's disease)
    - Any other disease that affects muscles you use to swallow.
- Your brain has been injured or damaged by disease.

Long-term tube feeding is not likely to help if:

- Your swallowing problem is due to dementia that is getting worse.
- Cancer is certain to end your life within a few months.

Choosing long-term tube feeding can be a challenge.

Take some time to think about your values, goals and beliefs. Ask your health care provider questions, talk with family and friends, consult your faith community.

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Long-term tube feeding facts - what you should know

Are there side effects with tube-feeding?

- Liquid food given through a tube can spill over into your lungs and cause a severe infection.
- Fluids can build up if your body cannot process food and water as it should, making you feel sick to your stomach (nausea).
- Fluid build-up in your lungs, stomach, hands and other places might cause discomfort.

What could happen if I do not try tube feed?

- Liquid food given through a tube can spill over. You may feel thirst, hunger or nausea.
- You may feel weak, drowsy or confused.
- Your mouth and lips may feel dry and/or sore.
- You may choke or get food stuck in your lungs.
- A severe infection can result.

What if I decide not to have a feeding tube?

You may worry about the effects of having no food or water. Talk about these fears with your doctor and loved ones. It may help to know the need for food and water becomes less and less in advanced illness.

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What should I keep in mind while I think about having a long-term feeding tube?

Rest assured that you and your family will receive the education and support needed to safely manage tube feeding. In case you have other worries, here is what you can expect:

Q. Will it hurt to have the tube put in?

A. The tube is thin. Placement involves minor surgery in most cases. Medicine will ease pain during and after placement.

Q. Will feeding cause pain?

A. No, they are gentle and many people sleep through them.

Q. Can I change my mind later?

A. Yes, you can always change your mind. Because you might not be able to say when to stop, talk with your doctor and those close to you. They need to know:

- Why you want to try the tube.
- What situations would make you want to stop tube feeding in the future.

What could happen if I do not try tube feed?

You may have a dry mouth and as sense of thirst. Proper mouth care and ice chips will be given for your comfort.

The choice is yours.

Tube feeding is one of many choices you can make to live as well as you can, as long as you live. If you decide not to try the feeding tube now, you can always change your mind later.
Take all the time you need to:

- Reflect on what is important to you.
- Share thoughts and concerns with your doctor and loved ones.
- Think about who you want to communicate on your behalf when you are no longer able to do so.
- Understand your options.

Whatever you decide, plans can be made to honor your wishes.