



# SETTING HEALTH CARE GOALS

*A Guide  
for People  
with Health  
Problems*

What **you** should know



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# What is important to you as you think about the future?

Different people want different things when they have serious health problems. What matters to you should guide decisions about your treatment. Talk with your health care team about what is important and what you want to accomplish. Your health care team can help you decide which treatments and services would best help you reach your health care goals.

## Ask yourself: What do I want from my health care?

You might want to:

- Stay as independent as possible
- Cure an illness, or improve the quality of your life when cure is not possible
- Prolong your life
- Get support for loved ones or caregivers
- Feel well enough to attend a special event, like a wedding or a trip
- Ease symptoms so you feel more comfortable
- Get support to stay at home

## What should I talk about with my health care team?

- Your medical condition – what it is and how it might change
- What is important to you – in your life, and about your health care
- Your health care goals – what you want your health care to help you accomplish or avoid
- Which services and treatments would likely help you reach your goals and be acceptable to you
- Support you might want – physical, emotional, spiritual
- Your health care surrogate – the person you want to communicate your decisions if you become too sick to speak for yourself

## Who should be part of the conversation with my health care team?

- Your health care surrogate – the person you want to communicate your decisions if you become too sick to speak for yourself
- Family members or others you trust who support you

## What can I do to get ready for a conversation about my health care goals?

- Think about what is important to you
- Think about the results you want from your health care
- Invite your health care agent and other people you trust to be with you during the discussion
- Bring your advance directive, if you have one, when you meet with your health care provider or team



# A message for people whose loved one is too sick to communicate their own health care decisions

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When a person is too sick to make decisions, the health care team relies on someone close to that person to help them understand what the person would want. If you are responsible for communicating health care decisions for someone else, your job is to tell the health care team *what that person would say* about their goals and the type of care they would accept. Their health care should match that person's *values, beliefs, and preferences*. If you don't know what those are, you should make decisions that are in that person's *best interests*.

## How do I know what the person who is ill would decide?

Think about what you know about them. What would they say is important to them now? What did they say about other people who were in similar situations? What did they say they would want, or would want to avoid? They might have completed an advance directive or life-sustaining treatment plan sometime in the past. Those documents can help you understand what their goals and preferences would be now.

Communicating health care decisions for others, even when you know what they want, can be stressful. The health care team can help you by providing information and support.



# Information About Life-Sustaining Treatments

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## What are life-sustaining treatments?

Life-sustaining treatments might help you live longer when you would be expected to die soon. Examples of these treatments are **feeding tubes, mechanical ventilation, dialysis, and cardiopulmonary resuscitation (CPR)**.

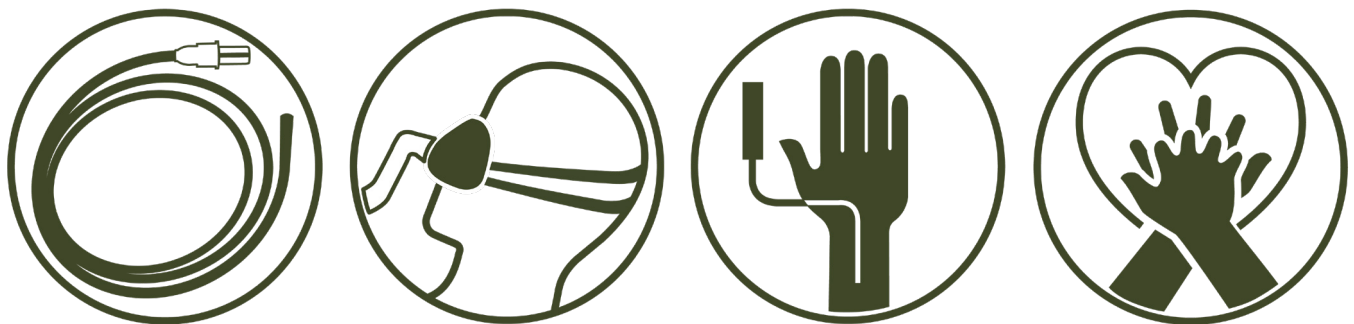
Life-sustaining treatments might or might not work to help you live longer. Whether they are likely to work depends on your medical problems. They do not cure disease or chronic illness. Sometimes they are used for a short time to get a person through a health crisis, like when a chronic illness suddenly gets worse or while a person is being treated for a sudden serious illness. They can help some people with certain medical conditions live for a long time. Sometimes they cause complications or discomfort.

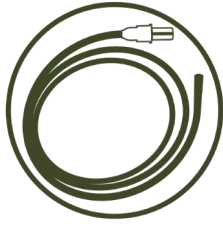
## Decisions about life-sustaining treatments

Some people would want life-sustaining treatments, and others would not. Some people would want some life-sustaining treatments but not others.

Decisions about life-sustaining treatments should be made based on your goals and your preferences.

**Your health care team can give you more information about life-sustaining treatments. Talk with them about how these treatments relate to your condition and your health care goals.**





# Information for Patients and Families About Feeding Tubes

## What is a feeding tube?

A feeding tube carries liquid nutrition, fluids, and medications directly into your stomach or intestines.

One kind of feeding tube goes into the nose, down through the throat, and into the stomach. It is about one-eighth of an inch in diameter.

Another kind of feeding tube goes through your skin into your stomach or intestines. Putting in the tube requires a minor procedure or surgery.

## When might a feeding tube be considered?

A feeding tube might be considered if you:

- Can't eat enough to meet your body's need for nutrition
- Can't eat safely due to swallowing problems

These problems might happen if you are very sick, have brain damage, or have health problems that effects your nerves and muscles. If you are expected to recover the ability to eat and swallow, a feeding tube might be considered for a short time. If you are not expected to recover the ability to eat and swallow, a permanent feeding tube might be considered.

Sometimes people who have trouble eating on their own (for example, someone with dementia or muscle weakness) can get more nutrition when someone helps feed them. In those cases, a feeding tube might not be needed.

If you have a severe illness that cannot be cured and gets worse over time, getting weaker and not being able to eat enough on your own can be a sign that you are getting closer to dying. Some diseases, in the very late stages, cause your organs to stop processing food and water normally. In those cases, a feeding tube might not help you feel better or live longer.

## Benefits and Risks

### What are some possible benefits of a feeding tube?

Depending on your condition, a feeding tube might prolong your life.

When your swallowing problem is expected to get better, having a feeding tube for a short time can help improve your nutrition. For example, a short-term feeding tube might help if you are recovering from a surgery or receiving a treatment that makes your throat very sore.

Long-term feeding tubes can help if your swallowing problem is caused by damage to your nerves or muscles.

You do not need to be in a hospital to receive fluid and nutrition through a feeding tube.

With some swallowing problems, there is a danger that food or fluids could go "down the wrong pipe" and go into your lungs. It is not clear that feeding tubes help reduce this risk.

### What are some possible risks of a feeding tube?

Feeding tubes can cause bleeding, infection, skin irritation, leaking around the tube, nausea, vomiting, and diarrhea.

The tube can get blocked or fall out and need to be replaced in a hospital.

You might find the tube to be uncomfortable.

You might inhale fluid into your lungs with a feeding tube. This could cause pneumonia.

Depending on your condition, the feeding tube may not help you feel better, gain weight, become stronger, or live longer. There is no evidence that feeding tubes help people live longer when they are in the last stages of a severe and incurable illness such as dementia or cancer.

# Information for Patients and Families About Feeding Tubes, continued

## What to Expect

### What if I have trouble eating or swallowing and **I have a feeding tube?**

If you are awake and aware of what's going on, having a tube down your nose and throat can be somewhat uncomfortable. It is usually not painful, and many people get used to it over time.

Having a tube that is placed through your stomach wall is not usually painful, and you can hide it under your clothes.

It is harder to get around when liquid is flowing through the feeding tube.

If you get confused, you might pull on the feeding tube. To prevent this from happening, you might be given medication to make you sleepy, you might have cloth wrapped around your mid-section to keep the tube in place, or you might have your hands covered or restrained.

You would receive care to help you be as comfortable as possible.



### What if I have trouble eating or swallowing and **I do not have a feeding tube?**

Sometimes people who have trouble eating enough on their own can get more nutrition when someone helps them eat. You might continue to take in your favorite food and drinks, with help if needed, as long as you wanted to eat and were able to do so.

You would receive care to help you be as comfortable as possible. Without fluids or nutrition at all, some people might feel hungry or thirsty at first and others may not. You might be given ice chips and mouth swabs to keep your lips moist. The amount of time a person can survive without food depends on their health, body weight, and whether or not they are taking in fluids. Some people who are not eating at all but are taking sips of water have been known to live up to 20-40 days. Some people who are eating small amounts and drinking fluids might live for years. Without any fluid, people might die within days to weeks.

In the last stages of severe, incurable illness, when death is near and a person is no longer taking in food or water by mouth, families often worry that the person will “starve to death.” In fact, for people with those medical problems, no longer taking in food and water is a natural, non-painful part of the dying process. In this case, the person is not dying because they have stopped eating, rather they have stopped eating because they are in the dying process.

**Your health care team can tell you if you are at risk for problems with eating or swallowing. Talk with them about treatment options that will support your goals and preferences.**





# Information for Patients and Families About Dialysis

## What is dialysis?

Dialysis filters a person's blood to remove waste products when their kidneys can no longer do the job. Dialysis is a type of life-sustaining treatment.

## There are two main types of long-term dialysis:

**Hemodialysis** is the more common type of dialysis. In hemodialysis, your blood flows through a tube outside of your body into a filter to remove waste products. A needle is inserted into one of the blood vessels, usually in your arm. The needle is attached to a tube that carries a steady flow of your blood into the filter. After the blood is filtered of waste products, it returns to your body through a second needle that is inserted into another blood vessel. Each session lasts about four hours and must be repeated at least three times a week.

In **peritoneal dialysis**, your blood is cleaned when waste products pass out of the blood vessels of your intestines into clean fluid that is flushed in and out of your belly. Clean fluid from a bag flows through a tube that goes through the skin of your belly into a space inside, around your intestines. The fluid stays there for several hours, and waste products from the blood pass into it. The fluid containing waste products then drains out through the tube and is thrown away. This process is repeated several times a day, or each night while you are sleeping.



# Information for Patients and Families About Dialysis, continued

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## When Might Dialysis Be Considered?

In many people with long-standing kidney disease, the problems slowly get worse over time. Dialysis would be considered when your kidneys can no longer remove enough waste products from the blood to keep you feeling well, and a kidney transplant is not available. You might feel sick to your stomach, tired, and weak. You could have little appetite and might have swelling. It might be hard to breathe or think clearly. Dialysis might help to partly relieve these symptoms.

Kidney problems may also come on quickly. If a severe illness causes the kidneys to fail or suddenly get worse, dialysis might be considered to help clean the blood during that time. Sometimes the kidneys start working again after the severe illness has passed. Other times, the kidneys don't start working normally again, and long-term dialysis may be needed after the severe illness has passed. The kidneys are more likely to begin working again if the person's overall recovery from the sudden illness is good.

## Benefits and Risks

### What are some possible benefits of dialysis?

Dialysis may prolong your life, depending on your other health problems.

Dialysis may help you feel better. You may feel less sick to your stomach, tired, or weak. You may have less swelling. Your appetite may get better. You may have fewer problems breathing or thinking clearly.

Unless you have other health problems that would prevent you from being active, you might be able to go back to work and participate in activities that you enjoy.

If you are eligible for a kidney transplant, dialysis can keep you alive while you wait for a donor.

### What are some possible risks of dialysis?

You may feel dizzy, tired, or have cramping after dialysis.

Access to your blood vessels (for hemodialysis) or the tube into your abdomen (for peritoneal dialysis) may get blocked. This can cause discomfort, and you may need a procedure to fix the problem.

You may be more likely to get infections, and suffer from heart disease and other medical problems. As a result, you may need to come into the hospital more often and stay longer. These problems can also increase the risk of death.

For people with some medical problems, dialysis does not help them live longer or feel better.

## What to Expect

### What if my kidneys fail and I have dialysis?

You may choose dialysis when your kidneys can no longer remove enough waste products from the blood to keep you feeling well.

If your kidneys fail quickly, a tube will be placed into one of your blood vessels. The tube carries a steady flow of your blood through a filter to clean it. This may be done daily or as needed until your kidneys get better. If your kidneys do not get better, you and your health care team will discuss whether long-term dialysis will help.

For long-term dialysis, you would need surgery to prepare the blood vessels in your arms (for hemodialysis), or surgery to have a tube placed into your belly (for peritoneal dialysis).

Most people receive long-term hemodialysis in a hospital or in a dialysis center, usually three times each week. You may be able to have hemodialysis at home if you have a trained helper. During each hemodialysis session, you would sit next to a machine that removes waste products from your blood. Each session lasts about four hours.

Peritoneal dialysis is usually given at home, and may also be given while a person is at work or traveling away from home. To have peritoneal dialysis, you must be able to do it yourself or have someone who can help you. Peritoneal dialysis is repeated several times a day, or each night while you are sleeping.

# Information for Patients and Families About Dialysis, continued

## What to Expect

### More about what to expect with dialysis...

If you receive dialysis, you would have to be careful about the types of food you eat. You would need to limit the amount of salt and certain other foods that you eat, and how much water you drink.

Medicines may be needed to control blood pressure, treat anemia, and prevent bone and heart disease.

You would have to adjust your schedule to allow time for dialysis.

Dialysis is not as good as healthy kidneys at filtering your blood. As a result, you may not feel well.

Most people receiving long-term dialysis have a shorter than normal life span.

### What if my kidneys fail and I do not have dialysis?

Most people can live for some time with kidneys that are only partly working. When the kidneys are not working properly, waste products slowly build up in the bloodstream. This might make you feel sick to your stomach, tired, and weak. You might have little appetite and have swelling. You would receive care to help you be as comfortable as possible.

When a person's kidneys become very weak, death may occur within days to weeks. Death from kidney failure usually involves feeling less and less awake and may result eventually in coma. You would be given treatments to manage discomfort from pain or fluid build-up to help you be comfortable.

**Your health care team can tell you if you are at risk for kidney failure. Talk with them about treatment options that support your goals and preferences.**





# Information for Patients and Families About Mechanical Ventilation

## What is mechanical ventilation?

Mechanical ventilation helps you breathe when you can't breathe on your own. It doesn't fix the problem that causes you to have trouble breathing. Being able to breathe on your own again depends on whether the problem that causes your breathing trouble improves.

## There are two types of mechanical ventilation:

**Non-invasive mechanical ventilation** helps you breathe by pushing air through a mask that is placed over your nose and mouth. Straps keep the mask in place. A machine pushes air and oxygen through the mask, and the pressure of the air helps you breathe. One type of non-invasive mechanical ventilation is called CPAP (continuous positive airway pressure) and another is called BiPAP (bi-level positive airway pressure).

**Invasive mechanical ventilation** uses a machine to push air and oxygen into your lungs through a tube in your windpipe. The machine is often called a ventilator. The tube goes through your mouth or nose, or through an opening that has been made in your throat, through your windpipe to your lungs. The tube is about as big around as a dime.



# Information for Patients and Families About Mechanical Ventilation, continued

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## When Might Mechanical Ventilation Be Considered?

CPAP or BiPAP might be considered if you need some help breathing.

A ventilator might be considered if your breathing problems are more severe. A ventilator is used to breathe for you when you can't breathe on your own.

Mechanical ventilation might be considered if you have:

- New or long-term severe lung problems
- Brain damage
- An injury to your spinal cord
- Severe weakness of the muscles in your chest

You might need mechanical ventilation for a few hours, a few days, or the rest of your life, depending on your condition. At first, it might be hard to predict how long you would need it.

## Benefits and Risks

### What are some possible benefits of CPAP, BiPAP, and a ventilator?

They might make it easier for you to breathe.

They might help you breathe while you recover from a serious illness.

They might prolong your life, depending on your condition. People with some conditions live for years using mechanical ventilation.

### What are some possible risks of CPAP and BiPAP?

You may have a dry nose and sore throat. You may have a runny nose, congestion, and sneezing. You may get nosebleeds.

It may irritate your eyes and the skin on your face.

You may have abdominal bloating that causes discomfort or nausea.

### What are some possible risks of a ventilator?

A ventilator places a person at high risk for infections.

You might find a ventilator to be uncomfortable. You might try to pull the tube. To prevent this from happening, you might be given medicine to make you sleepy or your hands might be restrained. Some people who need a ventilator do not recover to be as healthy as before.

You would need a lot of help. Most people on a ventilator need to be monitored in an intensive care unit or similar setting. Some people can be cared for in a nursing home or in their own home if they have care from professionals with the proper training.

## What to Expect

### What if my breathing problems get worse and I use CPAP or BiPap?

You would wear a mask over your nose, or over both your nose and mouth. Straps would keep the mask in place. The mask would be connected to a tube and a small machine that would push air into the mask.

You could remove the mask if needed.

You would be able to eat and talk.

### What if my breathing problems get worse and I do not use CPAP or BiPAP?

If you choose not to use CPAP or BiPAP, you would receive care to keep you as comfortable as possible. You would be offered medications to help you relax so that you do not feel like you have to struggle for breath or feel any discomfort.

# Information for Patients and Families About Mechanical Ventilation, continued

## What to Expect

### What if my breathing problems become severe and **I use** a ventilator?

A tube would be placed in your windpipe through your nose or mouth and connected to the ventilator. The ventilator would push air through the tube into your lungs. You would receive care to keep you as comfortable as possible.

You might find a ventilator to be uncomfortable. You might need to take medication to make you sleepy, or have your hands restrained if you try to pull on the tube.

If you need the ventilator for more than about two weeks, you would need a short surgery to place a hole in your neck where the breathing tube would be placed in your windpipe. This hole in your neck is called a tracheostomy.

You generally cannot talk, eat or drink while on a ventilator, and nutrition would be provided through a feeding tube. In some cases, people who are on a ventilator for a long time can be fitted with tubes to allow them to eat and speak.

Some people who are on a ventilator for a long time can get around in a special wheelchair.

If you need a ventilator for a long time, you might be able to go to a nursing home or your own home if you have professional care to monitor and maintain the ventilator.

### What if my breathing problems become severe and **I do not use** a ventilator?

You would receive care to keep you as comfortable as possible. You would be given medicines to help you relax or sleep. This would help you feel comfortable and not feel like you have to struggle for breath.

If your lungs fail completely and you have decided not to use a ventilator, you would probably die within minutes or hours.

If you are on a ventilator and decide to stop, you might die within minutes, although you might live for several hours. Sometimes a person unexpectedly survives for several days or even longer.

**Your health care team can tell you if you are at risk for serious breathing problems. Talk with them about treatment options that support your goals and preferences.**





# Information for Patients and Families About CPR

## What is CPR?

CPR stands for cardiopulmonary resuscitation. It is sometimes used in an emergency when someone's heart has stopped beating adequately. Cardiac arrest is another term for when the heart stops beating.

If you are in cardiac arrest, blood stops flowing through your body.

This means that oxygen cannot get to your brain or other organs. Your brain can survive without oxygen for only about five minutes. After that point, you would have permanent brain damage, even if your heart started again.

CPR can help blood and oxygen flow in your body while medical staff try to get your heart to beat normally again. This may help prevent brain damage.

CPR may include:

- Someone pushing on your chest with their hands (chest compressions)
- Someone giving you medications to stimulate your heart
- A machine giving you one or more quick electrical shocks to your chest (defibrillation)
- Someone pushing air into your lungs, either from their mouth into yours (mouth-to-mouth), or using a small bag attached to a mask. Someone may put a tube down your throat to open your airway if air is not reaching your lungs without it.



# Information for Patients and Families About CPR

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## When might CPR be used?

You would only get CPR if your heart stopped beating (cardiac arrest). Cardiac arrest can be expected or unexpected. It is a normal part of the dying process. Cardiac arrest could happen unexpectedly because of a sudden severe illness or injury, or due to a heart problem that the person may or may not know about.

Health care staff would automatically do CPR if you went into cardiac arrest, unless you have a Do Not Resuscitate (DNR) order. A DNR order tells health care staff not to do CPR if you go into cardiac arrest.

You have a choice about whether or not you would get CPR when your heart stops beating. Your choice about CPR does not effect the care you will receive or your decisions about other treatments.

## Benefits and Risks

### What are some possible benefits of CPR?

CPR can save lives, especially when given to a young, relatively healthy person right after their heart stops. After CPR, some people return to about the same health they were in before their heart stopped. This is more likely if the person does not have serious health problems, and if CPR is started quickly after their heart stops.

CPR might or might not work to re-start your heart. It is more likely to work if you are relatively healthy before a cardiac arrest. The chances of surviving are a little better if CPR is started quickly after the heart stops and if you receive CPR in the hospital. About 18 out of 100 people who get CPR while in the hospital survive their hospital stay, and about 82 out of 100 people die. Survival chances for you may be more or less, depending on your health problems.

### What are some possible risks of CPR?

CPR often does not work to re-start the heart, especially when given to someone who has more than one illness or a very serious disease.

If you survive after CPR, you may have a sore chest or broken ribs because of the chest compressions. You may have a collapsed lung. If your heart re-starts after CPR but you do not start breathing on your own, you would need a breathing machine (ventilator) to help you breathe.

If you do not get enough blood to your vital organs during cardiac arrest and you survive after CPR, you might have serious problems afterward. You might have brain damage or be dependent on others to care for you.

## What to Expect

### What if my heart stops?

If you have a cardiac arrest, you would lose consciousness and pass out quickly. Once you passed out, you would not feel anything.

If you do not receive CPR, or if CPR does not work to restart your heart, you would die. If CPR works to restart your heart but you do not start breathing on your own, you would be put on a breathing machine (ventilator), unless you have a doctor's order stating that you do not want to be on a breathing machine. If CPR works to restart your heart, you would receive medical care to treat any problems caused by CPR. Some possible risks of CPR are listed on the page before.

**Your health care team can tell you if you are at increased risk for cardiopulmonary arrest. Talk with them about treatment options that support your goals and preferences.**



# Tell Us What Matters to You

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Talk with people you trust and with your health care team about what is important to you, and what you want to accomplish through your health care. Based on your priorities, your health care team can help you decide which services and treatments would – and would not – be likely to help you reach your goals.

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