

Advance care planning



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Your life, your choices

What makes life meaningful for you? It's an important question that only you can answer. When you take the time for advance care planning, you ensure that your medical care and treatment will be consistent with your wishes should you become unable to speak for yourself.

Advance care planning aligns your current health with your values, beliefs, goals, culture and relationships to determine how to approach your future health care needs.

Advance care planning is not just about old age. Healthy adults can prepare for sudden, severe illness or injury such as a car accident that could leave them unable to make their own health care decisions.

A doctor's story

An elderly woman with difficulty breathing was transported to the Emergency Department of our hospital. Given her level of consciousness, she was unable to give any medical information to the doctors caring for her. During the initial evaluation, it was found that she was in acute pulmonary edema (swelling in the lungs caused by fluid). To treat her, she would need assistance with breathing. Her doctors placed her on a BiPap machine to help her breathe better, and she was transferred to the intensive care unit.

The patient's son was contacted and came to the bedside. He had a copy of her advanced directive which outlined her medical wishes, including a desire not to be placed on life support. Thankfully, her breathing improved, and she eventually returned home; but had her condition worsened, her son knew what to do. Fortunately, this story had a happy ending, but many do not. Too often families are ill-prepared for the decisions that must be made.

I cannot stress enough the importance of families communicating with each other about potential medical treatments — what they would and would not want — before an event or emergency occurs. Once you put it in writing, talk to your physician about your decisions. Advance care planning allows you and your family to be prepared and gives your loved ones peace of mind during an otherwise stressful time.

Michael Dunn, M.D., M.S.A., F.C.C.P.
Pulmonary/critical care medicine
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What is advance care planning at Henry Ford Health?

Too many of us spend our last days in ways we would never choose. Henry Ford Health encourages community members to have important conversations about end-of-life wishes while healthy or before it's too late. We believe that part of providing good health care is informing people about what their choices are and allowing time for consideration.

Our trained facilitators guide conversations that help you and your loved ones explore:

- **Who you are:** What is most important to you, including your faith and values.
- **Where you are:** Your current health and risk factors that could impact your future health.
- **How you want to approach future needs:** Considering different possibilities and treatment options for each.

The facilitator also explains how to complete an advance directive, which records your future health care wishes in a legal document.





What is an advance directive?

An advance health care directive is a legal document that spells out how you want to be treated if you become very ill and cannot speak for yourself. It can become part of your medical file.

It also names a “health care advocate,” the person you choose to make medical decisions for you if you are unable to make them yourself. A health care advocate

is an adult family member or friend who knows you well and can be trusted to do what is best for you. Your health care advocate should be someone who can be there for you when you need them and can clearly communicate with your health care providers about the decisions you’ve put in place through your advance care directive.

Including loved ones in the conversation

Perhaps the most important part of advance care planning is having a conversation that includes both your doctor **and** your loved ones. Engaging family or close friends helps them to understand, support and follow any treatment preferences that are made.

Health care planning is not only a smart thing to do for yourself; it is a compassionate thing to do for your family. Making your wishes known before a crisis occurs relieves the heavy burden on others of making difficult and emotional choices on your behalf.

Often, families pursue aggressive treatments and put patients through a lot of physical distress when there is no hope of meaningful recovery to avoid making a tough decision. With an advance directive, they’re able to carry out choices that you have previously made for yourself — and hopefully discussed with them in advance — so they’re not left with guilt over decisions they are forced to make.



Where to start

Your advance care planning facilitator will guide you through different scenarios to help you determine what is of greatest value to you and to match treatment options with priorities in a variety of situations.

Values driven advance directives

- **Life is of ultimate value.**
I want everything done to prolong it.
- **Quality of life is my ultimate value.**
Do reasonable things to restore quality of life but do not prolong my life unnecessarily.

- **Comfort is of ultimate value for me right now.**
I want nothing done to prolong my life;
I just want to be made comfortable.

Your decisions will likely be different at age 40 than at age 85. They may vary if you have an incurable condition as opposed to being generally healthy. An advance directive may be updated as you get older or if your viewpoint changes.





A personal testimonial

Serving as a chaplain, I have walked alongside many people battling chronic or terminal diseases. This time was different; the battle was close to home.

Mom was in her early seventies and full of life. Her hobbies included bowling, golfing, dinners with dad and friends and casino trips. Stage IV lung cancer came out of nowhere.

At first, the shock of the diagnosis was overwhelming. Finally, she and I agreed that while she couldn't control the illness, she could, to a large degree, control how she responded to it. We talked about what brought her meaning and made her life worth living. We considered her future medical needs and treatment that would allow her to live the aspects of life she enjoyed most.

We also had difficult talks about hospice and where and how she wanted to spend her last days. Looking back, those were the most precious conversations I'd ever had with my mom. I grew to really understand this feisty lady who had raised me.

Knowing her wishes allowed our whole family to focus on living — and when the time came to make decisions, we knew what she wanted. Mom died a peaceful, pain-free death with family at her side.

I guess that is why I now do what I do. While I can't change what is happening to those with a devastating illness, I can help impact how they experience it. Through thoughtful planning, a stressful and anxious time for families can be exchanged for a peaceful, precious time with their loved ones.

Jim Kraft

Compassionate care: A guide to life-sustaining treatments

The better informed we are, the better decisions we make. The following pages provide basic information on common life-sustaining medical procedures, an explanation of when they are most effective and potential complications.

For some people, it is most important to prolong life. Others may only want procedures that could get them back to a good quality of life. Your advance care planning facilitator can answer questions and offer further details to help you make the best choices for your situation.

Breathing machines

What are they?

Mechanical ventilation is provided by placing a tube through your mouth or nose and into the lungs. The tube is connected to a machine called a ventilator, respirator or breathing machine that forces air into your lungs.

When is a breathing machine used?

- When you can no longer breathe well enough on your own because of a disease
- As a temporary treatment during or after surgery
- To allow the lungs to rest while an illness is being treated

- To help you breathe when you are not able to take enough of your own breaths to meet your body's needs or during and after CPR

What you should know

People using a breathing machine are not able to talk using their voices. A conscious person may communicate through writing or hand gestures. Activities are limited.

A person on a breathing machine cannot eat. If a breathing machine is needed for a long time, you may need a feeding tube inserted into your stomach for food.

People approaching the end of life are less likely to be helped by a breathing machine.

If someone is very sick or weak, it may take months before the person is strong enough to get off of a breathing machine. Even with a breathing machine, some people get worse and die.

Possible complications

A breathing machine can cause throat discomfort, damage to vocal cords, fear and sleep problems.

Some complications of using a breathing machine may include pneumonia, collapsed lung, lung damage or infection.

Using a breathing machine requires constant medical care.

A breathing machine may be used on a trial basis to see if you can recover the ability to breathe. If your condition does not improve or gets worse, a decision can be made to remove the breathing tube.

If you decide not to use a breathing machine, you can still receive all other treatments you and your doctor think are right for you. You can have other breathing treatments and medicines to improve breathing.

Your comfort would be the primary goal. If you were to stop breathing after other treatments, doctors would allow natural death.

If you do not want to use a breathing machine, you should share your wishes with your doctors and family.

CPR

What is it?

CPR is an attempt to restart your heart if you stop breathing or your heart stops beating. CPR may include:

- Someone pushing on your chest and breathing air into your mouth.
- Shocking your heart with electricity or injecting medicine into your bloodstream.
- Inserting a tube down your airway and into your lungs to help you breathe.

CPR often requires follow-up in a hospital emergency room — most likely an intensive care unit (ICU) — so that a breathing machine and a heart monitor may be used.

What you should know

How well CPR works depends on:

- why your heart stopped
- how healthy you were before your heart stopped
- how long your heart was stopped before CPR begins

A healthy person whose heart stops suddenly because of an accident or heart attack has the best chance (15-20 percent) to return to good health after CPR. CPR is also more successful in the hospital, where healthcare workers can act quickly.

Older people are less likely to recover and more likely to have a heart that does not respond to CPR.

- Only five percent of nursing home patients live after CPR, even when performed in a hospital.
- Two percent of dementia (memory loss) patients survive.
- People with late stage cancers have only about a one percent chance to live through CPR.

Possible complications

CPR is not as easy as it seems in the movies and on television.

- Many people suffer broken ribs from CPR attempts.
- Half will have brain damage that will never get better.

Other complications may include bruising of the chest, burns on the skin from shocks, lung damage and bleeding in the chest, damage to the windpipe or esophagus and damage to lips and teeth from the breathing mask and tube.

It is important to think about your chances of living through CPR and what life might be like after CPR. If you choose not to have CPR, you would still be able to get all other medical treatments that you and your doctor think are right for you. If your heart were to stop, doctors would allow natural death.

If you do not want CPR, you should share your wishes with your doctors and family.

Tube feeding

What is it?

When people have difficulty swallowing or are too sick to eat on their own, a feeding tube provides liquid nutrition. A temporary feeding tube (NG tube) is placed through the nose into the stomach. A PEG tube is placed surgically through the skin and into the stomach or intestines when needed for longer periods of time. Food and water are slowly and gently pumped through these tubes.

For people with a mouth or throat problem who are expected to recover soon, a feeding tube may ease the pain of eating. People with brain or nerve disease, or an injury or disability that causes problems swallowing may also benefit.

For people near the end of life, a feeding tube may not prolong life. Near the end of life, it is natural to lose interest in eating or drinking and to stop digesting food as body functions begin to shut down.

Possible complications

When the body cannot use the nutrition that a feeding tube provides, the tube may cause:

- bloating, cramping, diarrhea
- nausea and vomiting
- water build up in the legs
- water build up in the lungs, making it difficult to breathe

People with conditions such as late stage dementia may feel anxiety, become agitated, and try to pull the tube out. They may need to have their hands tied down to avoid harming themselves.

What you should know

People worry that a patient will “starve” if they do not get a feeding tube. People who stop eating or drinking because they are sick are often dying from a disease. These people die from the disease, not because they are not eating.

Tube feeding may be tried on a trial basis. When the decision is made to place a feeding tube, you can also agree to monitor its continued use. If things don’t go as hoped, you may decide to stop tube feeding.

If you choose not to be tube fed, you will be kept comfortable with small sips of water, ice chips and wetting of your mouth and lips.

If you do not want tube feeding, you should share your wishes with your doctors and family.



Questions to consider:

What is your understanding of your state of health?

What health problems do you worry you may develop in the future?

What scares you most about medical treatment?

Do you hold any cultural or religious beliefs or values that would influence end-of-life choices?

Is cost a factor in your medical care decisions?

What factors might change your medical treatment priority from trying to prolong your life to focusing on comfort while being allowed to die?

Who do you trust to be your voice if you can no longer make decisions for yourself?
Are they willing to accept that responsibility?
Do you have an alternate choice in case your first choice is unable to represent you?

What information is important for you to share with loved ones?

Contact your primary care provider for forms and information to help you get started with advance care planning.