

Advance Care Planning

Communicating Your Healthcare Wishes



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To talk to someone about advance care planning:

- Scan the QR code with your phone, or
- Type in the URL www.sanfordhealth.org and search advance care planning.

Getting Started

Why Is an Advance Care Plan Important?

Advance care planning is the process of deciding your own future health care. It makes sure your wishes will be carried out if you cannot speak for yourself. An advance directive is the document that outlines your wishes in case of a major illness or injury.

Everyone over the age of 18 should have an advance care plan.

Why Do I Need an Advance Care Plan?

Think about this situation: You become suddenly ill or injured. You are getting all the medical treatments needed to keep you alive. But, your doctors believe there is little or no chance you will be able to know who you are or know those around you.

- Who will make your decisions for you?
- What do you want the goals of your care to be?
- What kinds of treatments do you want to continue or to stop?
- How can you help your loved ones make these decisions?
- Are you concerned about the costs of medical treatments?

Such a situation might arise at any age because of an injury to the brain from an accident, a stroke, or a slowly progressive disease like Alzheimer's. Your loved ones may be frightened, overwhelmed, and confused about what your wishes are.

When doing advance care planning, people may make statements that are not very clear and do not provide enough information to guide decision making about your health care. These may include comments like:

- "If I'm going to be a vegetable, let me go."
- "No heroics."
- "Do everything possible to keep me alive."

Advance care planning is different for everyone. For example, what does being a "vegetable" mean to you? Or, what does "heroic" medical care mean to you? Or how long should "everything possible" be done? Expressing your wishes clearly is important for those who will make decisions for you.

If you would like help to state your wishes clearly, contact your health care provider for a consultation, or set up an appointment with a trained Advance Care Planning Facilitator in your area.

Advance care planning may lessen your suffering and may bring peace of mind to you and to those who may be making your decisions.

Choose a Health Care Agent

Choosing your health care agent or decision maker is a very important step. This person does not need to be the same person as anyone associated with matters of your finances or estate. Your health care agent's duty is to see that your health care wishes are followed.

- If your wishes are not known, your agent would try to decide what you would want.
- Your agent's choices for you will be honored before anyone else's wishes for you.
- Your agent will make health care decisions for you only if you cannot make your own decisions.

Note: Legal requirements for health care agent's may vary by state. See the included advance care plan document for specifics.

Tips for Choosing an Agent

Your health care agent should:

- Be someone you trust
- Know your wishes well
- Speak up on your behalf when you cannot speak
- Honor your wishes

Choose an Alternate Agent

It is a good idea to choose a second person to be an agent in case your first choice is not available when needed. After choosing an agent, ask your agent to read or photocopy the letter on the next page to give your agent more information about the responsibilities of being an agent.

Use this space to list possible agents, their addresses, and phone numbers before filling out the legal form.

A Message for My Health Care Agent

I have chosen you to be my health care agent. A health care agent is a person who knows my treatment wishes and is willing to carry them out after one or more doctors decide that I cannot make my own decisions. You will need to learn what is important to me. I will need to talk with you about my choices. I plan to write down my decisions about my care in an advance care plan. I will give you a copy of the plan.

Thank you for being my agent.

What You Can Do

Restrictions on what an agent can and cannot do vary by state. Together, we will check my state laws. In most states, as my agent, you can:

- Choose or refuse life-sustaining and other medical treatment for me.
- Consent to and then stop treatment if my condition does not improve.
- Access and release my medical records.
- Move me to another care center and choose my health care provider.
- Request an autopsy and donate my organs, unless I have stated otherwise on my advance care plan.

Being my health care agent does not give you control of my money or responsibility for my bills.

Questions to Ask Yourself

- Am I willing to take on this role and responsibility?
- Do I know the person's wishes for future health care?
- Can I make the decisions the person would want me to make, even if my views are different?
- Can I make important health care decisions under stressful situations?

If you answer "No" to any of these questions, talk to me about your concerns.

If You Are Not Comfortable With Being My Agent

We can talk about your feelings and concerns. The more information you have, the more confident you will feel about making decisions for me. There may be ways to help you feel more comfortable making decisions for me.

- You may want to come to a doctor's appointment with me. You will be able to ask questions about my health condition and health choices that may arise.
- Review my advance care plan. Make sure that I have clearly stated my wishes.
- You may want to visit with trained professionals who help people make health decisions. They include advance care planning facilitators, social workers, case managers, and religious and spiritual leaders.

Consider What It Means for You to Live Well

Gather your thoughts using this **optional** worksheet. Consider your future health care needs and values before you fill out the advance directive.

Reflect on Your Beliefs and Values

1. If you were having a really good day, what would happen on that day? Who would you talk to? What would you do?

2. What helps you face serious challenges in your life?

3. What role does religion, faith, or spirituality play in how you live your life?

4. If you have significant health problems, what are they and what do you fear in the future?

5. Considering future medical treatments, what would you not want to happen to you?

6. How does cost influence your decisions about medical care?

7. When would you want the goals of medical treatment to switch from trying to prolong your life to focusing on comfort? Describe these circumstances in as much detail as possible.

8. What does a natural death mean to you?

9. How much are you willing to go through to get more time?

10. How will you know when enough is enough?

11. What are your greatest worries or fears?

Learn More About Possible Medical Treatments

The following are medical treatments that may be used to save or extend your life. Each of these treatments can be successful if they are used as a bridge to your recovery. When you are approaching the end of your life, using them could cause you to suffer without hope of recovering the ability to know who you are or who you are with.

CPR (Cardiopulmonary Resuscitation)

CPR refers to the methods used to try to restart the heart and lungs if they stop working.

- **CPR** is used to try to restart your heart if it stops beating. It involves pressing down on your chest and breathing into your mouth.
- **Intubation** is used if you cannot breathe. A tube is placed through your mouth or nose into your windpipe. The tube may be attached to a breathing machine (ventilator). The machine pumps air through the tube and into your lungs.
- **Electric shocks (defibrillation)** may be used to send brief shocks to your heart through small pads on your chest. It may help restore your heart rhythm to normal.
- **Medications** may be used to help restart your heart.

What Is the Likely Outcome of CPR?

CPR can save lives, but the success rate is low. Your age, health, and illness can affect the outcome. When CPR is started on older, weaker people in nursing homes, about 1 out of 30 survives. CPR works best if you are in mostly good health and it is started quickly. When it is started in the hospital about 1 out of 5 survives. Even if you survive, complications can occur during CPR that may cause more health problems. Health care after CPR may involve care in an ICU (intensive care unit) for:

- A ventilator to support breathing
- Damage to your ribs
- Possible brain damage from being without oxygen

How Do I State My Decision About CPR?

In the hospital, your doctor and other health care providers will do CPR when needed unless you tell them not to or have your wishes written in an advance care plan. If you choose not to have CPR, a **Do Not Resuscitate (DNR)** order is written by the doctor. This order tells health care providers not to do CPR if your heart and lungs stop working. You may change this decision any time.

What if I Do Not Want CPR?

If no medical treatment is done, your heart stops beating and you will have a natural death.

Ventilator or BiPAP

A ventilator can be used for a few hours to a few months or years.

- A **ventilator** is a machine that helps a person breathe. The machine is connected to a tube that goes through your nose or mouth and into the windpipe. It pushes air into your lungs if you are too weak to breathe on your own.
- **BiPAP** (bi-level positive airway pressure) is a machine that pushes air into your lungs through a face mask that fits tightly over your mouth and nose.

Possible Concerns With Ventilators or BiPAP

- You may need to be cared for in an intensive care unit (ICU).
- You may need medicine to keep you drowsy or asleep.
- You cannot speak or swallow when the ventilator tube is in your windpipe.
- The ventilator may not work well if your body is shutting down from long-lasting health problems.
- For long-term use, the breathing tube may be placed into an opening made in your throat (tracheotomy).
- With a BiPAP mask, some of the air may go into your stomach and cause gas pain. Wearing a mask may make it difficult to talk or eat.

What if I Do Not Want a Ventilator or BiPAP?

If you are not able to breathe on your own or with a breathing machine, you will die naturally. You will be kept comfortable.

Kidney Dialysis

Dialysis is a treatment that does the work of the kidneys by filtering the blood. There are 2 types of dialysis:

- **Hemodialysis** removes fluids and wastes from the blood using a filter. Blood flows from your body to the dialysis machine then through a special filter, called a dialyzer or an artificial kidney, and back to your body again. As blood goes through the dialyzer, fluid and wastes are taken out.
- **Peritoneal dialysis (PD)** is a treatment for kidney failure that uses the body's own peritoneal membrane in the belly as a filter. PD is done about four times every day at the normal breaks in the day: morning, noon, evening, and bedtime.

What Happens if I Choose Not to Have Dialysis?

All patients have the right to decide not to start dialysis. If you started dialysis, you have the right to stop. Choosing no treatment or stopping dialysis will cause a natural death within a few days to a few weeks. You may be able to start dialysis again if you change your mind.

Artificial Feeding or Artificial Hydration

Artificial feeding (feeding tube) or artificial hydration are used to support your body if you can no longer take in food or fluids by mouth. Some types of tubes used include:

- **An NG tube (nasogastric)** can be placed through the nose and into the stomach. It sends formula and water directly to the stomach.
- **A G tube (gastrostomy) or PEG tube (percutaneous endoscopic gastrostomy)** can be placed through a small hole in the belly. It sends formula and water directly into the stomach.
- **An IV line (intravenous)** line is placed into a vein. It sends nutrition and fluids directly into the blood vessels.

Possible Concerns About Artificial Feeding

Risks can include bleeding or infection at the tube site and problems with the tube. Inhaling the formula by accident can cause pneumonia, a life-threatening problem. A swollen belly, belly discomfort, and diarrhea can be burdens of tube feedings.

What Happens if I Choose to Have Artificial Feeding?

Artificial feedings may help you feel better and improve your quality of life for a time. If you are near the end of your life, it may be hard to tolerate the problems that can occur with the treatment.

What Happens if I Choose Not to Have Artificial Feeding?

If you cannot take in any food by mouth and choose not to have artificial feeding, your body will slowly shut down. Death will likely occur within a few days or weeks. You may find it reassuring to know that most patients near the end of life do not typically feel hunger or thirst.

Possible Concerns About Artificial Hydration

Artificial hydration can cause too much fluid to build up in the body. This can cause uncomfortable swelling in the arms, legs, and belly. Fluid can also build up in the lungs, which can cause trouble breathing and shortness of breath. Risks also include bleeding and infection at the tube site.

What Happens if I Choose to Have Artificial Hydration?

Artificial hydration may help your body function. This may increase comfort and improve quality of life for a time. If you are near the end of your life, you may find it hard to tolerate the problems that can occur with this treatment.

What Happens if I Choose Not to Have Artificial Hydration?

Without enough fluids, the body will slowly shut down. Death will occur within a few days or weeks. You may find it reassuring to know that dehydration is a natural part of the dying process. Most patients near the end of life do not feel thirsty. In the last days of life, dehydration may help trigger the release of chemicals in the brain that can leave you with a sense of calm and well-being. This may help you pass your final hours in greater comfort.

Deactivation of Cardiac Devices

Implanted cardiac defibrillators (ICD) or left ventricular assistive devices (LVAD) can be used to support your heart function. There may come a time when you wish to deactivate these devices and have a natural death. It will help to talk to your doctor about this ahead of time and have a plan in place.

Antibiotics for Infections

Sometimes death occurs as a result of an infection rather than a medical problem such as cancer or heart disease. Some examples of serious infections are pneumonia and sepsis. You can decide to treat infections or not depending on your wishes and long-term health outcome. Antibiotics are medicines used to treat infections caused by bacteria. Other medicines can be used to treat viruses or fungal infections. These medications may need to be given through an IV.

Palliative Care and Hospice Care

You may want to include your wishes about where and how you would like to receive care.

Palliative care is a method of providing comfort care. The goal is to prevent or treat symptoms and side effects of a disease. It should be part of the plan from the first day a serious illness is diagnosed. Palliative care can be provided regardless of how long you are expected to live. Palliative care can provide:

- Relief of pain and other symptoms
- Emotional and spiritual support for you and your family
- Help with making complex treatment decisions

Hospice care is a level of comfort care provided to those who are expected to die within the next 6 months. The focus is on symptom management, a peaceful death, and life after death. As your health declines, hope shifts to the meaningful time with family and friends. Hospice care can give all the benefits listed for palliative care plus:

- Physical therapy or occupational therapy to help develop new energy or conserve energy
- Art, music, and other complementary therapies
- Respite care to provide a break for caregivers
- Home health aides to help with bathing, grooming, eating and other personal health needs
- Trained volunteers for support like running errands and meal preparation
- Support services for caregivers including grief counseling

Organ Donation

Consider these facts about organ donation when making your decision. Register at www.life-source.org or place your wishes on your driver's license.

- More than 3000 people in the upper Midwest are waiting for a transplant.
- Organ donation may help your family in the grieving process. One person can save or heal up to 60 lives.
- There is no cost to you or your family when you donate organs.
- Even if you have health conditions, you will likely be able to donate.
- All major religions support organ donation.
- Organ donation will not affect any funeral plans for viewing.
- Organ donations are confidential.

Donating your whole body to science may require separate forms.

To learn more, visit us online:

good-sam.com

sanfordhealth.org



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