

Frequently Asked Questions about Advance Care Planning

What is Advance Care Planning?

Advance care planning means planning ahead for how you want to be treated if you are very ill or near death. Sometimes when people are in an accident or have an illness that will cause them to die they are not able to talk or to let others know how they feel. Texas law allows you to tell your doctor how you want to be treated by using an advance directive. Chapter 166 of the Texas Health and Safety code is the state law on advance care planning through advance directives. Chapter 166 explains advance directives, includes forms to use for advance directives and states how medical decisions can be made when a person does not have an advance directive.

Advance care planning is a 5-step process.

- Thinking about what you would want to happen if you could not talk or communicate with anyone
- Finding out about what kind of choices you will need to make if you become very ill at home, in a nursing home or in a hospital
- Talking with your family and doctor about how you want to be treated
- Filling out papers that spell out what you want if you are in an accident or become sick
- Telling people what you have decided

Questions and Answers about Advance Care Planning

If I get too sick to say what kind of help I want from doctors or nurses, what can I do?

Putting your wishes in writing makes sure that everyone knows what you want. You can do this using a form called the *Directive to Physicians, Family and Surrogates*. This form is also sometimes called a *Living Will*. The form tells doctors, family members or other people who are close to you the type of help you want when you are sick and how you want to be treated. The document includes written instructions on things that you do want and DO NOT want done to you.

Do I have to fill out this form?

No. No one can make you fill out the form. But with it the people helping you will know what you want if you can't tell them.

Can I change my mind about what I say on the form?

Yes. You can do that at any time you want. If you change your mind, you must make out a new form and throw away the old one rather than make changes to the old form. That way no one will make a mistake when they are trying to help you.

It is also a good idea to tell your family and doctor that you have changed your wishes.

Remember, this form can only be used when you can't tell people what you want. If you are awake and able to say what you want, then that is the only thing that matters.

Can someone speak for me if I am not able to say what I want?

Yes. You can fill out a form called a *Medical Power of Attorney*. This form lets you name someone to speak for you. The person you name is called an *agent* on the form. You can choose anyone you want to be your agent. It does not have to be a member of your family. But remember, it is always important for your family and agent to know what you want before something happens to you.

If you don't name someone to be your agent, then state law has a set of rules for how decisions will be made for you.

What are the rules?

Do I need a lawyer to fill out any of these forms?

No. You can fill them out yourself. You can ask a lawyer to help you, but you do not have to. Once you have filled out the forms, all you have to do to make them legal is sign them in front of the proper witnesses. You do not need a notary public.

Do doctors, nurses and hospitals have to follow my instructions?

Yes, unless they inform you in advance that they cannot. If they do not intend to honor your wishes, they are required to give you a reasonable opportunity to or assist you to transfer to a physician or health care provider who will comply with your wishes. Health care professionals cannot simply ignore your wishes.

Other Questions about Hospitals and Nursing Facilities and Treatment at the End of Life

Sometimes people have questions about when it makes sense for them to move from a nursing facility to a hospital. The following information tries to answer some of those questions.

If I'm in a nursing facility and get very sick, should I stay where I am or go to the hospital?

This is a choice you will have to make after you talk to your doctor or family members. If you can get the care you need where you are, it is often safer and more comfortable to stay in the nursing facility. Moving to the hospital can cause problems because the people working there do not know everything about you. Sometimes this leads to problems with medications, pressure sores and infections. Ask your doctor if there are things you need that the nursing facility can't do for you. Make sure you understand all the risks in moving or staying where you are.

What is an Out-of-Hospital Do Not Resuscitate Order (OOHDNR)?

This form is for use when you are not in the hospital. It lets you tell health care workers, including Emergency Medical Services (EMS) workers, NOT to do some things if you stop breathing or your heart stops. If you don't have one of these forms filled out, EMS workers will ALWAYS give you CPR or advanced life support even if your advance care planning forms say not to. You should complete this form as well as the Directive to Physicians and Family or Surrogates and the Medical Power of Attorney form if you don't want CPR.

What is Cardiopulmonary Resuscitation (CPR)?

You have probably seen this on TV. CPR is pressing on your chest to keep blood flowing and also assistance with breathing, such as mouth to mouth assistance. Sometimes electrical shocks are used to help start the heart. CPR is only used for short periods until a person can get to the hospital.

Does CPR always work?

No. It depends on other things, including your overall health and your age. Everyone is different. It does not work very well for most people who have a life-threatening illness or are over 80. You should talk about CPR with your doctor and discuss what is best for you and what best fits with your personal values and goals.

What is Artificial Respiration or Ventilation?

This means getting assistance with breathing when you can't breathe on your own. A tube is put into your nose or mouth or into your windpipe. If this tube is needed for more than a few weeks, a surgeon will probably need to put the tube directly into your throat. Doing this causes problems with talking, eating and drinking. The tube is also attached to a machine, which makes it harder to move around.

Eating, Drinking and Pain During a Terminal Illness

What is Artificial Nutrition and Hydration?

These are medical treatments that allow a person to get food and water when they cannot eat or drink. Fluids can be given through a needle placed in a vein (IV). This is usually done for only a few days because of the risk of infection and because it is hard to keep the needle in place. Sometimes food and water are given through a tube that goes down the nose and throat into the stomach. If the tube needs to be in place for a long time, it is placed directly into the stomach by a surgeon.

These different kinds of tube feeding are different from ordinary eating and drinking because they don't let the person taste or feel food and liquids like they are used to doing. Also, the person is not in control of their food or liquid intake. Doctors and nurses decide how much food and water they should have in this way.

Do Artificial Nutrition and Hydration Make People Live Longer?

Sometimes, but not always. How effective these kinds of treatment are depends on other medical problems. When a person with a terminal illness can't eat or drink it usually means that the body has stopped working like it should and it will not improve. If this is the case, tube feeding alone will not make the person healthy again. It may even make the person uncomfortable during their final days.

What about Pain and Comfort?

If a person has a medical problem that will cause them to die and they don't want artificial treatment, they can still be comfortable. Making people comfortable during the final part of their life is called *palliative care*. Even if there is no cure for a condition, doctors can treat pain, nausea and discomfort. Comfort should always be part of the treatment plan that a doctor discusses with a patient or family.

The importance of Advance Care Planning

Everyone is going to die sometime, but not everyone gets to choose how they are treated at the end of their lives. Taking the time to do advance care planning can help family members and medical staff act for you. They will be faced with hard decisions near the time of your death. Having an advance care plan lets you make sure that you are treated according to your values and wishes regardless of whether you can speak for yourself.