

ADVANCE CARE PLANNING is the *process* of helping people to understand the importance of preparing **for future medical care**. It is good to discuss your personal choices with family, loved ones, and doctors. These people should know your **personal values, goals, and spiritual or cultural beliefs**. This planning process is important for older Americans or those who have a serious illness. *It is also very important for healthy younger adults who may lose the ability to speak for themselves because of trauma or a sudden and unexpected illness.*

ADVANCE CARE PLANNING means sharing your story.

This will help in the process of shared decision making among patient, family, doctor and others. **In almost everyone's life there will be difficult choices about medical treatment.** If you are unable to speak for yourself, those you love will be much less burdened if they can know what you would desire, instead of guessing about what you would want. Advance care planning *is an ongoing process*, not just the completion of one document. Texans are independent; they like to control their own lives. However, they rarely like to think about or discuss the final phase of life. As a result, they and their families are often unprepared for the sometimes difficult and distressing decisions that must be made.

Yet like most Americans, Texans also have strong feelings about what they consider **quality care during the dying process**. Surveys consistently show that people desire a peaceful death, free from pain, suffering, or a prolonged period of dependence. Achieving that "good end of life" has much to do with decisions that are made by individuals, their family members, and health care providers. **Advance care planning** is a way to address these issues and **to ensure that your values, wishes, and choices are known and respected.**

Advance care planning is the process by which an individual considers his or her personal values about the dying process, discusses those values with family or others close to them and health care providers, and completes the documents that record those decisions for the future. While this process is important for all age groups, **some of the most difficult decisions involve young people**. Between the ages of one and 44, the most common cause of death is trauma (motor vehicle accidents, homicide, suicide, drowning). Such causes of death or profound, severe, permanent damage cannot be predicted. For this reason, ***EVERYONE needs advance care planning, not just older or chronically ill people.***

Seniors are an important population for **advance care planning** not only because they are involved in the majority of end-of-life decisions, but also because at times they have no spouse or family member to speak on their behalf. And even when close family members are available, they do not automatically know your wishes. Studies have shown that spouses guess wrong more than half the time about what kind of treatment their husband or wife would want. You can help assure that your wishes will direct future health care by participating in **advance care planning**. The best way to approach this process is to think about these important issues when immediate decisions are not necessary and there is not great emotional stress.

Advance care planning involves two basic parts. The first is to decide what you want. To do that, you must understand what kinds of situations you may face and what options for care exist. But because it is impossible to predict every situation or illness, it is helpful to think in general about the **quality of life** that is important to you. These types of decisions are deeply personal and should be based on your values and beliefs.

The second part of **advance care planning** is to communicate with others. Tell your family, others close to you, and your health care providers what kind of care you would want in different situations **Write your wishes down** so that they are available if in the future you are not able to make your choices known. Consider who

might best know your wishes and make decisions for you if you are unable to do so.

Advance Directives are the documents used to help a person express his or her wishes and values about medical care in case the person cannot, at some future time, speak for him or herself. In Texas, there are three commonly used documents to record this information. These forms are not required, but are recognized by health care providers. You may wish to use other documentation which is more detailed, but the Texas directives offer a good starting point.

They are: the **Texas Directive to Physicians, Families or Surrogates** (commonly known as a “living will”), the **Medical Power of Attorney**, and the **Out of Hospital DNR (Do Not Resuscitate) Order**

- Advance directives do NOT require a lawyer or a notary public.
- Advance directives are free.
- Advance directives require witnessing and, in the case of the Out of Hospital DNR, a physician’s signature.
- Advance directives take effect only when you are unable to express your wishes for yourself.
- Advance directives are reversible.

The **Texas Directive to Physicians, Families or Surrogates (“Texas Directive”)** allows a person to indicate choices about treatment in the event of a terminal or irreversible disease or condition. This document records for your physicians, family, and others what your wishes are if you are unable to speak for yourself.

For example: Mr. L has suffered a severe stroke. He is paralyzed and unable to take care of himself or communicate in any way. Additionally, he has pneumonia and will probably die if he does not receive intravenous antibiotics. He may also need a breathing machine. The doctor thinks he has little chance of returning to normal, but he has a fair chance of getting over the pneumonia. Mr. L’s family members disagree about what they should do. His son believes his father was never a quitter. He thinks his father would have chosen to fight as long as there was the slightest hope for cure. Mr. L’s daughter disagrees and thinks that although her father wasn’t a quitter, he wanted to die naturally. She thinks he would be horrified to be kept alive this way. Mr. L had completed a directive stating his wish that if he were in a condition where he was totally dependent and had little chance of recovery, he would not choose life-sustaining measures such as the use breathing machines, feeding tubes, or medications other than those that would make him comfortable. His family and health care providers, therefore, are able to make the decision not to give antibiotics or use a breathing machine, and they can be comfortable in the knowledge that this is what he wants.

In the above example, Mr. L’s directive made it possible for him to:

- clarify the treatments he did and did not want;
- resolve a disagreement among family members; and
- relieve some of the stress, guilt, and emotional burden for his family.

Without his written directive, those providing care for him and his family would have been faced with the difficult job of determining his wishes, and they would have never known if they were right. His written guidance allowed his family to be assured they were making the decision he would have wanted.

The Texas Directive specifically allows you to choose whether you would like life sustaining treatments in two situations: a terminal condition or an irreversible condition. Understanding these terms and what they might

mean for you is essential in making your advance directive. Your health care provider may also be able to assist you by explaining these terms and how they may apply to your individual health history.

Life sustaining treatment is any treatment, procedure, or medicine that doctors believe is maintaining the patient's life. Without it, doctors believe the patient will die. Examples include use of life support equipment such as breathing machines and kidney dialysis, medications, heart pacemakers, feeding tubes, fluids provided through a vein (artificial nutrition and hydration), and blood transfusions.

Sometimes medical care, whether it is a treatment, medication, or a procedure such as an operation, is provided to make the patient more comfortable or to prevent or manage pain. Such medical care is not considered life-sustaining treatment and may be provided to all patients. It is also important to understand how hospice care differs from life-sustaining treatment.

Hospice care is providing a “gentle”, natural death by controlling pain and other physical symptoms, and by providing emotional and spiritual support to dying persons and their families. Under the hospice philosophy, death is neither hastened nor postponed, and procedures that seek only to prolong life without relieving pain or suffering are not appropriate.

A **terminal condition** is an incurable disease, illness, or injury that doctors expect will cause death within about six months even with life-sustaining treatment. Some examples of the conditions that are generally considered terminal are certain types of cancer when the disease is extensive, widespread, or treatment is not effective; advanced heart, liver, or lung disease; and severe injuries.

An **irreversible condition** is a disease, illness, or injury that cannot be cured although it may be treated. Many irreversible conditions will reach an advanced stage when they will also be considered terminal. Many illnesses or injuries, such as cancer; kidney, heart, liver, or lung failure; and serious brain damage or dysfunction caused by stroke, injury, or Alzheimer’s dementia, are irreversible, but patients may be kept alive for prolonged periods of time with life-sustaining treatments.

As you think about the concepts of terminal and irreversible conditions and life-sustaining treatments, it is important to remember that it may no longer be possible to make a person well or return the person to his or her previous state of health or independence. **In those situations, treatments or machines that support organ systems may also cause suffering and prolong the dying process. Only you can decide whether or not you would like the goal of your care to be focused on providing comfort rather than delaying a natural death, and if so, at exactly what point.**

In your Texas Directive, you have the opportunity to explain your wishes and include additional requests (for example, particular treatments that you do or don't want) and even to appoint a spokesperson to make health care decisions for you (a spokesperson can also be appointed in the Medical Power of Attorney document that will be explained later). **An appointed decision maker cannot over turn your Directive to Physician, other written instructions, or your know wishes and desires – written, verbal, or inferred.**

Many people worry that if they complete an advance directive, they will not receive treatment that they want. It is important to remember that your directives only take effect when certain criteria are met: first - you are unable to make your wishes known and, second (in case of the Living Will), a doctor has stated in writing that

you are in a terminal or irreversible condition. It is also good to remember that you can change your directives at any time.

For example: *A man with severe emphysema had been in the Intensive Care Unit (ICU) at the hospital many times, but is now home, and needs oxygen just to stay comfortable while sitting. His doctor told him that it was likely his breathing would get worse again at some time in the near future, and that it was very likely he would be in the ICU on a breathing machine again, unless he chose not to be, and that this might be where he dies. The man was no longer enjoying his life. He was very limited in his activities because of severe shortness of breath even while sitting still. In addition, he wanted to be at home for his last days. For all these reasons, he signed a living will. It directed his doctors and family to give him anything necessary to keep him comfortable, but not to take him back to the ICU if he were to get sick again. Now his youngest child is getting married in two weeks. Even though his condition has not changed, the patient states, "Well, I've made it this far, I want to do everything I can to be here for the wedding." This statement may represent a reversal of the advance directive. After clarification of his wishes, this verbal reversal takes priority over the written document that he signed before. **In other words, once a living will is filled out, it can be changed by a patient.***

The second advance directive document in Texas, the **Medical Power of Attorney (MPA)**, allows a person to name someone to make decisions in the event that the person is unable to do so. This is important when there is a problem you did not predict and address in your living will. This document is especially helpful if the person you would choose to make choices for you is not your legal next of kin. This document is different from a general power of attorney and does not allow the person to make decisions about your money or property.

Texas has two powers of attorney - financial and medical - they are not reciprocal, one cannot do the other.

For example: *A man with severe emphysema after many years of heavy smoking is on a breathing machine in the ICU for the sixth time. After 10 days, he is not getting better. He is divorced and has three children, one of whom is a nurse. In his MPA, he chose the daughter who is a nurse to make decisions for him when he was unable to communicate for himself. Assuming that he had not specified in a Texas Directive what he wanted done in this situation, she would be responsible for deciding. This would relieve the burden of making decisions from his other children, who might be less familiar with this kind of situation. His family would suffer less uncertainty, and this might help them adjust to his eventual death more peacefully.*

The MPA allows the person you appoint to make specific treatment decisions in **accordance with your wishes**. In complex and rapidly changing medical situations this can be very important. Many people fear spending extended periods of time on organ-support equipment in intensive care units when dying. But some would be willing to be put on a breathing machine (for example) for a short period of time (several days perhaps) **if there were a good possibility that they could recover to their previous state of health and independence**. Your MPA would allow the person you appoint to evaluate the situation and make decisions that you would make in that specific situation (**not terminal or irreversibly ill**) without dishonoring your written and known wishes.

Two important points about the person appointed to be your MPA:

- The person you choose must know your wishes, desires, beliefs, and values.
- The person you choose must be willing to follow your wishes. If your wife, son, or friend tells you he or she couldn't make the decision to withhold organ-sustaining treatment even if that were your wish, that person should not be your MPA. Health care providers must follow your known wishes.

For example: *Mr. R. is a widower with no children who is undergoing treatment for lung cancer. His closest friend, Mrs. J., visits him daily, and they have talked extensively about his wishes as he comes to the end of his life. Mr. R. develops an infection and a high fever that has made him delirious, and as a result he is unable to make his own decisions. Mr. R.'s next of kin is a brother who lives in another state and Mr. R. has never discussed these issues with him. By naming Mrs. J. as his medical power of attorney, Mr. R. can make sure she will be the one to decide on his behalf. Otherwise, Mrs. J. has no legal standing, and the patient's brother would be responsible for making these decisions.*

The third type of Texas advance directive is called the **Out of Hospital DNR Order**. It is used most commonly when a person has a life-threatening or terminal illness and does NOT want a 911 emergency resuscitation in the event that he or she dies. This does not apply in the inpatient hospital setting, but does apply at home, in a nursing home, at a grocery store, in a hospital emergency room, in an outpatient clinic, or in an ambulance leaving the hospital to go home. Unlike the other two, this directive may be executed by a surrogate for an incompetent patient.

For example: *A woman with advanced ovarian cancer and has chosen not to have curative treatment. She is still able to get around a bit and enjoys grocery shopping. She would like not to die an agonizing and painful death, with blockage of her intestines, spending her final moments in the hospital. Like most of us, she would prefer to go suddenly. She filled out an Out of Hospital DNR and wears the wristband. While grocery shopping one day, she stops breathing and is found on the floor. A kind person calls 911. When the EMTs arrive, they find the bracelet, treat her for comfort, and allow her to go in peace, just as she wanted. They notify her family.*

Two witnesses are required to sign all of your Texas advance directive documents. One of these witnesses must be someone who is NOT:

- someone related to you;
- a person having a claim to your estate;
- the person appointed to be your spokesperson in the document;
- your attending physician or one of the physician's employees; or
- a person providing direct care to you or employed in the business office of a health care facility where you are a patient.

In addition, a doctor's signature is required for the Out of Hospital DNR Order form. If you have questions about advance directives in Texas, there are many resources to assist you. Your health care provider or local hospital may be able to answer your questions or refer you to someone who can.

This information is provided to comply with the Texas Advance Directive Act and the Federal Patient Self-Determination Act. Complaints may be filed with the Texas Department of Health, 1100 West 49th Street, Austin, Texas 78756 (18002281570).