ADVANCE CARE PLANNING



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ATTORNEY GENERAL OF TEXAS GREG ABBOTT

ADVANCE care planning*

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.

* The Office of the Attorney General thanks Cheryl Ellis Vaiani, Ph.D., for contributing the material for this booklet. Dr. Vaiani is an Assistant Professor and Clinical Ethicist of the University of Texas Medical Branch in Galveston.

ADVANCE advance CARE care PLANNING planning

Yet like most Americans, Texans also have strong feelings about what they consider quality care at the end of life. 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 end of life, discusses those values with family or others close to them and with 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 end-oflife 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-oflife decisions, but also because at times they have no spouse or family member to speak on their behalf. 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. Numerous resources can help you examine and explore your views. Your health care provider; the Veterans Health Administration; local, state, or national organizations interested in end-oflife care; and the Internet are all good sources of information

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 you are not able to make your choices known in the future. 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 people express their wishes and values about medical care in case they cannot, at some future time, speak for themselves. There are three documents available in Texas to record this information. They are: the Texas Directive to Physicians, Families or Surrogates (formerly known as a "living will"), the Medical Power of Attorney, and the Out of Hospital DNR (Do Not Resuscitate).

- 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 guitter. He thinks his father would have chosen to fight as long as there was the slightest hope. 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.

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If Mr. L had completed a directive stating his wishes, his family and health care providers could have avoided this situation.

In the above example, a directive would have made it possible for Mr. L 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 an attempt to provide a "gentle" 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 reliev<mark>ing pain or</mark> 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 lifesustaining 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 life 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 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).

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 directive only takes effect if two criteria are met: first, that you are unable to make your wishes known and, second, that 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 directive 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. that unless he chose otherwise it was very likely he would be in the ICU on a breathing machine again, 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 in his final moments. For all these reasons. he signed a Texas Directive. 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 Texas Directive is filled out, it can be changed, just by saying so.

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 explain in your Texas Directive. 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.

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 should he be 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 life-support equipment in intensive care units at the end of their lives. But some would be willing to be put on a breathing machine (for example) for a short period of time (several days to several weeks, 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 if you could.

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

- 1.The person you choose must know your wishes.
- 2. The person you choose must be willing to follow your wishes. If your wife, son, or friend tells you he or she couldn't follow your wishes, that person should not be your MPA.

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**. It is used most commonly when a person has a lifethreatening or terminal illness and does NOT want a 9-1-1 emergency response team to be activated in the event that he or she is dying. This document applies in an outpatient hospital setting, at home, in a nursing home, at a grocery store, in the emergency room, in an outpatient clinic, or in an ambulance leaving the hospital to go home.

FOR EXAMPLE: A woman with advanced ovarian cancer has enrolled in a hospice program. She is still able to get around a bit. She does not want to spend her final days in the hospital. She filled out an Out of Hospital DNR and wears the wristband.

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

- 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 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. Your local library and the Internet are also good resources. For more information and document forms, consult the resources on the back of this booklet.

REMEMBER these important points

- 1. Advance directives are for everyone, not just the ill and elderly.
- 2. Advance directives are free.
- 3. Advance directives are reversible.
- Advance directives work best when accompanied by family discussions of values.
- Advance directives prevent arguments and bad feelings at the end of life and help create a more peaceful bereavement for the survivors.



GREG ABBOTT Attorney General of Texas

FOR MORE information

ON THE INTERNET

Visit the **Senior Texans Page** of the Texas Attorney General's Web site at

www.oag.state.tx.us.

Texas advance planning documents are available for downloading and printing through a link from the Texas Attorney General's Web site.

BY U.S. MAIL

Office of the Attorney General P. O. Box 12548 Austin, Texas 78711-2548

BY TELEPHONE

Elder Law and Public Health Division (800) 806-2092