Planning for the future

Having an Advance Care Plan for health care is a smart thing to do. Like all planning for the future, it involves thinking ahead.

Most of us make plans for the future for all sorts of situations. In the health care setting, advance planning involves thinking about what you would do if you become so ill that you could no longer communicate with your loved ones or your doctors. You may be in excellent health right now, or you may have a chronic illness or a serious and incurable condition. But what if you were terribly injured or suffered a catastrophic illness and suddenly were unable to hear or speak with your loved ones or the doctors and nurses treating you?

WHO would work with your doctors and nurses to help make decisions for you? WHAT would those decisions be? The following information can help you answer these two very important questions.

Why have a plan?

Medical science has never been better at preventing and treating all sorts of illnesses. Thanks to great progress in medical science, people are living longer than ever before. Most of us are blessed to grow old.

At some point in time, however, even the most medically advanced treatments fail and end of life is inevitable. Most of us will pass through a hospital and/or nursing home in the last year before we die. When that happens, there are issues that we must be prepared to face.

PAIN AND SUFFERING:
No one should have to suffer their way to death. We encourage patients and families to work closely with health care professionals to improve pain and control other symptoms.

UNNECESSARY, NON-BENEFICIAL TREATMENTS:
We all want treatments that make us better, but no one wants ineffective treatments that don't benefit us. There is no evidence that those who receive more treatment at the end of life live longer.

TOO HIGH A FINANCIAL COST TO INDIVIDUAL FAMILIES AND SOCIETY. Health care costs at the end of life are a major source of personal bankruptcy, and Medicare spends 25 – 30 percent of all funds in the last year of life, one half of that in the last two months of life.[1]

Advance care planning and completing an advance directive can help us decide and communicate our wishes about how we want to be cared for when we are no longer able to communicate because of injury or illness.

What is advance care planning?

Advance care planning is a process for directing treatment at a time in the future when you can no longer make your wishes known. It involves conversations between you, your family and your health care providers. It is ideally initiated while you are relatively healthy, of sound mind and not under the stress of serious or bad news about your health. However, as long as you are able to communicate your wishes to your health care team or a family member or friend, it is not too late to initiate the process.

Advance care planning typically requires that you think about your values and preferences for treatment when cure is no longer possible and you can no longer make your wishes known. For example, if you are in an irreversible coma and the only way you can be kept alive is in a nursing home in a diaper with a variety of tubes placed in your body, would you wish to be kept alive like that?

Or consider a situation in which you are terminally ill and have the most severe pain. If the only way to lessen your pain requires such high doses of morphine that you are asleep all of the time until you die, is that acceptable as long as you are no longer in pain?

These are hard questions. If you have an incurable condition, what would be your goals of treatment?

Although patients do not want to die, they certainly don't want to suffer, receive ineffective non-beneficial treatment or cause serious financial strain for their family. When 344 seriously ill patients were asked to rank their most important desires near the end of life, the top three were: (1) freedom from pain, (2) peace with God and (3) presence of family. Other important goals were having finances in order, feeling that life was meaningful, resolving conflicts and dying at home.[2] Interviews of 126 patients living in a nursing home when asked the same question indicated they wanted: (1) good pain and symptom control, (2) to avoid inappropriate prolongation of the dying process and (3) to achieve a sense of control.[3]

What goals are important to you when cure and remission are no longer possible?

No two persons are alike, but below are some goals commonly expressed by others near the end of life. We hope these might help you think about your own goals when your time comes. These are offered in no particular order, but you might consider checking off those that are important to you:

- ☐ Saying goodbye to my family and friends
- ☐ Being free from pain
- ☐ Staying off machines
- ☐ Maintaining my dignity
- ☐ Not being short of breath
- ☐ Not dying alone
- ☐ Having someone to listen to me
- ☐ Not being a burden to my family
- ☐ Having a doctor and nurse who know me
- ☐ Being at peace with God
- ☐ Dying at home
- ☐ Having my financial affairs in order

Are there other goals important to you near the end of life?

I don't feel comfortable talking to my family and physicians about this.

Even though it might make you uncomfortable to talk about it, advance care planning is important if you want the best treatment as you near the end of life. Having an advance directive such as a Living Will is associated with less suffering at the end of life, less frequent hospitalization, improved patient/ family satisfaction and lower costs of treatment.

Remember, if you don't make the decisions, others will have to make them for you. It is certainly easier for your family or significant other if you let them know your wishes in advance. In the absence of advance care planning, families find making treatment decisions for terminally ill loved ones to be among the most stressful decisions in life and patients are much more likely to receive ineffective, painful, and expensive treatments prior to death.[4] Advance care planning is a blessing to you and your family.

But I'm not even sick. Why make an advance directive now?

We can never know what will happen tomorrow. Many experts believe that the best time to plan for the medical future is when you are healthy. You can always change your plans in the future.

I'm ready to make an advance directive. What are my next steps?

FIRST, DECIDE WHAT YOUR OVERALL GOAL IS IN SEEKING MEDICAL TREATMENT. What would you want your treatment team to do if you were in misery or unresponsive and they could not make you well enough to leave the ICU or hospital alive?

Would you want them to continue treatments that only prolong dying? What if these treatments are associated with suffering and high costs? Would your suffering or the cost matter to you? Or would you want your physicians to focus on your comfort?

Although some patients actually live longer when the goal changes from cure to comfort, others will die sooner when a machine or drug that is prolonging dying is removed. No matter what your preferences are, make certain the person you have chosen to speak for you understands your preferences.

THEN DECIDE WHO SPEAKS FOR YOU WHEN YOU CAN NO LONGER SPEAK FOR YOURSELF.
If something were to happen to you to leave you unable to communicate, who should relay your values to the doctors treating you? This could be a family member or any other person you trust to speak for you when you can no longer speak. This person is referred to as a surrogate. You must talk with this person (surrogate) and make certain they understand your values and treatment preferences. You want this person to know how much you need them to understand your wishes when you can no longer speak for yourself. You must share with them your answers to the questions discussed above.

FINALLY, COMPLETE THE ADVANCE DIRECTIVE.
An advance directive allows you to legally document the type of medical treatment you prefer at a time in the future when you are unable to make your wishes known. There are three types of advance directives in Texas to think about at this time:

- Directive to Physicians and Family or Surrogates (Living Will)
- Medical Power of Attorney
- Out-of-Hospital Do-Not-Resuscitate Order

A DIRECTIVE TO PHYSICIANS AND FAMILY OR SURROGATES (LIVING WILL) is a legal document that allows you to state your basic goals for medical treatment and the intensity of medical treatment at a time in the future when: 1) you are no longer able to make your wishes known and 2) your doctor has certified that you are terminally or irreversibly ill. Texas has one of the most patient-friendly Living Wills in the country and offers you two basic goals and treatment preferences in the setting of either a terminal or irreversible illness. You may express your preference for either:

- aggressive (even if burdensome) treatment to keep you alive in the terminal or irreversible condition, or
- comfort treatment only, allowing as gentle and peaceful a death as possible.

Note that this is your directive not only to the doctors treating you, but also to your family or your surrogate. A surrogate is the person chosen to speak for you if you are no longer able to speak for yourself. You may choose your surrogate or the law chooses one for you if you have not done so and you become unable to make your wishes known.

There are several different forms you may use for a Living Will. You may complete the formal Texas State Directive to Physicians and Family or Surrogates. You may seek independent legal or other advice and have your own unique living will drafted, or Baylor Scott & White Health can provide you with a simplified living will form.

WHAT IS A TERMINAL CONDITION UNDER TEXAS LAW?
Texas law defines a terminal condition as, “an incurable condition caused by injury, disease or illness that according to reasonable medical judgment produces death in six months, even with available life-sustaining treatment provided in accordance with the prevailing standard of medical care.”

Many serious illnesses may be considered incurable early in the course of the illness, but they may not be considered terminal until the disease is far advanced. Patients may live with an incurable illness for many years before it becomes terminal. Remember that even if your illness has reached a terminal stage, you and your physician will make decisions together as long as you are able to communicate. Your Living Will only becomes active when you are no longer able to communicate.

WHAT IS AN IRREVERSIBLE CONDITION?
An irreversible condition is defined in Texas law as, “a condition, injury or illness that: 1) may be treated, but which is never cured or eliminated, and 2) that leaves the person unable to care for or make decisions for that person’s own self, and 3) without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.” All three qualifications must be met for your Living Will to apply.

Many serious illnesses such as cancer, failure of major organs (kidney, heart, liver, or lung), and serious brain diseases such as Alzheimer's dementia, may be considered incurable early on. However, there can be treatments that slow down the disease and prolong life for some time. Later in the course of the same illness, the disease may be considered irreversible under Texas law when the patient is no longer able to make decisions or care for himself or herself, but the patient may still be kept alive without recovery for a long time before they finally die.

WHAT CHOICES CAN I MAKE WITH MY LIVING WILL?
For terminal and/or irreversible conditions, you may declare a preference for continuing life-sustaining treatment, or you may reject such treatment and request comfort care only that will allow you to die as gently and peacefully as possible.

In addition, there is a space in the Living Will to state additional wishes, including specific treatments you do or do not want, donation of your organs or tissues or the designation of a person to make decisions for you if you have not previously given a medical power of attorney to another person on your behalf. In Texas, Living Wills are effective until they are revoked. If you have an old Living Will and choose to update it, the document most recently completed will take priority.

WHAT IS A MEDICAL POWER OF ATTORNEY (MPA)?
A Medical Power of Attorney is a legal document that allows you to appoint an individual (an agent) to serve as your health care decision maker. This person may make a broad range of health care decisions for you at a time in the future when you are unable to make decisions for yourself. These health care decisions may include decisions to accept or reject life-sustaining treatment, whether or not a physician finds you irreversibly or terminally ill. Be very thoughtful about your choice for your Medical Power of Attorney. You are giving them a lot of responsibility and a lot of power. It is very important that the person you appoint as your Medical Power of Attorney knows your wishes for these circumstances.

WHAT IS AN OUT-OF-HOSPITAL DO-NOT-RESUSCITATE ORDER (DNR)?
Inappropriate or unwanted Cardiopulmonary Resuscitation (CPR) when you are an inpatient in the hospital is prevented when your doctor writes an Allow Natural Death or a Do-Not-Attempt-Resuscitation order. In the nursing home, home care, hospital outpatient department or other non-hospital setting, an Out-of-Hospital DNR order must be completed if you wish to prevent emergency medical personnel from performing CPR at the time of death. This type of advance directive is especially important to those who are irreversibly or terminally ill and who wish for a peaceful death. CPR is not useful in the setting of a terminal or irreversible illness. You may wish to review Baylor Scott & White Health informational handout on CPR.

WHERE CAN I OBTAIN A LIVING WILL FORM?
DOES IT COST ANY MONEY?
DO I NEED AN ATTORNEY?
You may request a Texas Directive to Physicians and Family or Surrogates (Living Will) form from a member of your care team. The form also is available to download and print from Baylor Scott & White Health consumer Web site: www.BSWHealth.com/PatientInformation, along with other resources that may help you with the process of advance care planning. Or you can download the form from the State of Texas Web site, http://www. dads.state.tx.us/news_info/ publications/handbooks/ index.html#handbooks.

You may download a Simplified Advance Care Plan and Living Will (Optional) form provided by Baylor Scott & White at www.BSWHealth.com/ PatientInformation.

The Texas Living Will is free and one of the most patient-friendly Living Wills in the country. You will find instructions for completing the form as well as relevant definitions directly on the form. It requires neither a lawyer nor a notary. There are many other Living Will forms available. You may wish to consult your faith tradition or an attorney. Texas will honor living wills from other states as long as they don't otherwise violate Texas state law and as long as they were validly executed in the other state.

For all practical purposes, Texas law recognizes Living Wills other than those requesting physician-assisted suicide or “mercy killing,” neither of which are legal in this state.

WHAT IF I NEED MORE HELP OR HAVE OTHER QUESTIONS?

Your physicians and nurses in the office or hospital can help you with many of your questions. If they don’t have the answers, social workers or hospital chaplains are also available to assist you. Baylor Scott & White has many free handouts on serious brain injuries, cardiac resuscitation, artificial nutrition, palliative care and related issues if you want more information. Finally, Baylor Scott & White hospitals have specialists in Palliative Medicine and Medical Ethics if you need additional help.

REFERENCES:

[1] 2003 CMS statistics and Last Year of Life study available at www.cms.hhs.gov.

[2] Steinhauser KE, Christakis NA, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000; 284: 2476-2482.

[3] Singer P, Martin D, Kelner M. Quality end-of-life care: patients’ perspectives. *JAMA*. 1999; 281(2):163-168.

[4] Tilden VP, Tolle SW, et al. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research.* 2001; 50(2):105-115.