

Important information about medical and ethical issues

If you are reading this guide, you are probably in the hospital or preparing to be in the hospital. Our goal while you are a patient in our hospital is to help you experience the best possible outcome from your stay here. For this to happen, everyone—you, your family and your health care team—must all work together and communicate clearly. This guide is provided to help you understand how you and your family can work with your health care team toward the goal of achieving the best possible outcome, as well as to help you understand what your rights and responsibilities are while you are a patient here.

We know that a hospital can be a confusing place. You may have many different doctors who visit when your family isn't nearby. Physicians and nurses may use words you don't understand. You may have questions about hospital rules or your rights as a patient. You may be very sick and hard choices may need to be made about your treatment. Making those decisions can be difficult and emotions may be strong. We hope the information you find in this guide will ease your mind, make you feel comfortable communicating with your health care team about your treatment or any other issues, and enhance the experience of both you and your family.

Your rights and responsibilities as a patient

As a patient, you have certain rights and responsibilities. As a hospital, it is our responsibility under federal law and hospital accreditation standards to make sure you are informed about those rights and responsibilities.

For example, you have the right to:

- information about your condition, treatment options and test results
- information about outcomes that may be different from what you and your family expected
- treatment for pain and suffering
- information about hospital ethics policies
- participate in your treatment decisions, including ethical decisions about treatment
- refuse or accept treatment or research that is offered to you. This includes the right to refuse treatments that can potentially help prolong your life, such as mechanical breathing machines, dialysis, artificial nutrition/hydration or attempted cardiopulmonary resuscitation (CPR)
- complete advance directives such as a living will or medical power of attorney. These forms can be obtained from your nurse, chaplain, social worker, or physician
- privacy, confidentiality, security and culturally respectful communication
- have a language interpreter to assist you with conversations about your health throughout your visit free of charge
- have access to items and/or devices to assist you with conversations about your health throughout your visit free of charge
- decide who may visit you during your hospital stay
- choose a primary support person to stay with you during your hospital stay
- be informed if family or guest visitation must be restricted
- freedom from mental, physical, sexual or verbal abuse or neglect
- a discharge planning evaluation to be sure your health care needs are met after you leave the hospital

With your rights come certain responsibilities. Your responsibilities, among others, include:

- the responsibility to give your health care team honest and accurate information about your medical history
- the responsibility to follow treatment directions and cooperate with your health care team
- the responsibility to treat other patients, visitors, your health care team and hospital property with respect

Who is on my health care team?

Throughout this guide we refer often to your health care team. Depending on many factors, your health care team may be made up of any number of individuals who will provide your care. Every team member brings special expertise to your plan of care. These individuals will identify themselves, their professional status if applicable, their relationship to others on the team, and their role in your treatment and care.

Goals and types of treatment

The most basic goal of medicine is to fix or cure your health problem. If a complete cure is not possible, the goal of the health care team is to try to slow down the problem or make it go away for a while (remission). Perhaps the most important goal is to provide you with comfort and relief of suffering at all times. You will receive medically appropriate treatment to meet these goals and we hope that you will do well.

Communicating with your health care team

Good communication is essential to every part of medical treatment. It is important when things are going well. It may be even more important when things are not going well and the outcome you and your family expected is not being achieved. Either way, it is vital that you, your family and your health care team communicate clearly. You should feel free to discuss any topic associated with your care and

treatment with members of your health care team. For example, you may want to discuss:

- your diagnosis
- goals of your treatment
- the types of treatment appropriate to meet those goals
- the benefits, burdens, and risks of treatment as well as the probability of success

It is important that you discuss your goals and the types of treatment with your physicians, nurses and your family while you are able to speak for yourself. How do you want to be treated if you have an accident or an illness and become so sick you can't speak for yourself? Who should speak for you and what should they say?

The importance of advance care planning

The process of thinking about who should speak for you if you can no longer speak for yourself and considering the goals and intensity of your treatment is called advance care planning. When thinking about who should speak for you, consider how trustworthy that person is and how available they are. Think about what you would want them to say on your behalf. This is easy if you are only temporarily unable to speak for yourself and recovery is expected.

But what if you become so sick that you can no longer communicate and cure is no longer

possible? If you make these decisions in advance, you will be relieving your family and loved ones from making these decisions for you. You should think about these questions:

- What physical, mental or financial burdens would you be willing to accept to temporarily stay alive longer (or prolong dying) in that circumstance?
- What quality of life would you want to have to make staying on a breathing machine or dialysis worth while?
- Would you be willing to live confined to a bed in a nursing home, unable to care for yourself?

- How important is pain control to you—not only physical, but mental and spiritual?
- What if you were permanently unconscious and could not feel pain, hunger, thirst, happiness, love or joy, but could be kept alive with a tube in the stomach to provide artificial nutrition and hydration?

These are hard questions and they often have deeply personal answers. Whatever your answers are, the best way to communicate them is by completing an advance directive such as a Living Will and/or a Medical Power of Attorney.

Advance directives have been clearly shown to improve patient care in the setting of serious illness and to lessen family stress. If you do not have an advance directive at the time of admission, we hope you will complete one prior to discharge. It

is never too late to do so, and a copy can be placed in your medical record. You are not required to complete an advance directive. Whether or not you choose to complete an advance directive, your care, treatment and services that you receive will not be affected, nor will your decision result in any discrimination against you.

To help you face questions you may have about advance directives and to complete an advance directive, you may request the following additional resources from your nurse, social worker, chaplain or physician, or you may access all of the following documents online at www.BSWHealth.com/PatientInformation.

- Advance Care Planning
- A Guide to Your Care
- Common Questions and Answers About Artificial Nutrition and Hydration
- Common Questions and Answers About Autopsies
- Common Questions and Answers About Cardiopulmonary Resuscitation (CPR)
- Common Questions and Answers About Hospice
- Common Questions and Answers About Pain in the Setting of Serious Illness
- Common Questions and Answers About Palliative Care

- Common Questions and Answers About Severe Brain Injury
- Information About Serious Illness
- Official State of Texas forms for a: Living Will (Directive to Physicians and Family or Surrogates), Medical Power of Attorney, Notice of Declaration and Declaration for Mental Health
- Out-of-Hospital Do-Not-Resuscitate Order
- Simplified Advance Care Plan and Living Will (Optional)

If I complete an advance directive, can I change my mind?

Yes, you may cancel any advance directive simply by destroying the document, signing and dating a written statement that states your desire to cancel the directive, or telling your doctor or nurse. You may also review and revise your advance directive. If you choose to change an advance directive, you must execute a new one.

Where else can I get help?

In addition to your personal physician, all Baylor Scott & White hospitals have specially trained social workers, nurses, and chaplains who can help you with advance care planning concerns. You may also have ethical concerns as you consider potentially serious issues. All Baylor Scott & White hospitals have access to ethics committees and ethics consultants who may offer counsel and assist in resolving ethical issues that might arise. These services are provided free of charge. You, your family or health care decision maker, your physician or any member of your health care team may request guidance from a Baylor Scott & White hospital ethics committee. For further information, your physician, nurse, social worker or chaplain can help you reach the ethics committee at your facility or you may call one of the phone numbers at the end of this handout.

You may also wish to consult your personal or family lawyer if you have questions about advance care planning.

What if there is disagreement about ethical issues?

On rare occasions there may be ethical disagreements between you, your family and/or health care providers. We believe good communication can prevent most ethical disagreements. It is also worth remembering the following:

- We will make every reasonable attempt to honor your treatment preferences within the mission, philosophy and capabilities of Baylor Health Care System hospitals and the accepted standards of medical practice. This includes those expressed by an advance directive or by others on your behalf if you lack an advance directive and are unable to make decisions.
- We respect your right to reject treatments offered.
- We do not recognize an unlimited right to receive treatments that are medically inappropriate.
- Texas law, specifically Chapter 166 of the Texas Health & Safety Code, provides a process for resolving ethical disagreements between you, your family, and/or health care providers in those rare cases where further communication does not resolve the disagreement. This process relies on ethics consultants and ethics committees available at each Baylor Health Care System hospital to help as needed.

At some point, you may be asked to make hard choices about treatment when cure of your illness is no longer possible and emotions may be strong. We have provided this information in hopes of helping you better understand your rights, responsibilities and ethical issues associated with being in the hospital. We hope a better understanding will improve communication, treatment and lessen stress for all.

Complaints

We welcome your feedback at all times, both positive and negative. If you have any complaints, we hope you will:

- First report your complaint to the clinical manager for the unit or facility involved. The bedside nurse will help you identify the clinical manager.
- You may also contact hospital administration at the number listed in the Contact Information contained in this document.

We will investigate your complaint through our formal complaint process and we will give you a response.

Although we encourage you to bring your concerns directly to us, you always have the right to take any complaint to the Texas Department of State Health Services and/or the Joint Commission by e-mail, fax, letter or phone at the contact numbers and addresses listed below.

Grievance Process Information

THE JOINT COMMISSION:

- E-mail: complaint@jointcommission.org
- Telephone: (800) 994-6610 weekdays 8:30 a.m. to 5 p.m., Central Time
- Fax: (630) 792-5636 Office of Quality Monitoring
- U.S. Mail:
Office of Quality Monitoring
The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, IL 60181

TEXAS DEPARTMENT OF STATE HEALTH SERVICES:

If you have any complaints concerning the information that we have provided in this document, you may contact:

Texas Department of State Health Services
(888) 973-0022 (toll free number)
1100 W. 49th Street
Austin, TX 78756-3199