

What you and your family should know

When a patient becomes seriously ill, the goal of the health care team is to help the patient improve and attain the best possible outcome. For this to happen, the patient, the family and the health care team must work together and communicate clearly. Hospitals can be confusing places, especially when dealing with the most serious illnesses.

- Patients may have many different physicians who visit them when family members are not nearby.
- Physicians and nurses may use words that are hard to understand.
- There may be questions about hospital rules or patient's rights.
- Emotions may be strong in the setting of serious illness and these emotions can complicate the hard decisions we must sometimes face.

During such difficult times, it is important for the patient and the family to have a clear understanding of their rights, responsibilities and choices.

The information contained here is intended to help guide you as you make serious decisions about your treatment or a loved one's treatment. While it cannot replace careful conversation with your physicians and nurses, we hope it will supplement those conversations and help improve communication between you and your family and the health care team.

Medical care today

We've never been better at preventing and treating disease and injury. Thanks to great progress in medical science, people are living longer than ever before. Most patients who enter a hospital will get better. Even seriously ill patients can improve.

At some point in time, however, even the most medically advanced treatments fail. Medical science cannot cure every illness. If a patient is sick enough to be in the hospital, especially in the Intensive Care Unit (ICU), the risk of death is about 20 times higher than the general population.

Each patient's individual characteristics have a major influence on their personal chance of improvement and survival. For example, although the overall cure rate for cancer is about 50 percent, some cancers are cured almost all the time while other cancers cannot be cured at all. Similarly, although most ICU patients will survive and attain a good outcome, if a patient's organs begin to fail, the chance of survival decreases, even with the best medical science.

When a patient doesn't do well

What happens when a patient doesn't do as well as we have all worked for and hoped?

In such circumstances, we must all face hard choices about treatment.

Sometimes a treatment intended to help ends up causing harm. This could include pain, other physical suffering, emotional disturbance, spiritual distress or even premature death. When treatment causes more suffering than it prevents, or prolongs dying instead of restoring health, should it be continued or stopped? Are we letting go of hope if we discontinue a medical treatment or if we decide against surgery, dialysis or a breathing machine?

These are hard questions. They challenge us not only medically, but also emotionally, ethically and spiritually. These questions can be troubling at any time but are especially hard without good information and good communication.

Facing end-of-life issues

Most of us are blessed to grow old. At some point, however, 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 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 between 25 – 30 percent of all funds in the last year of life, one half of that in the last two months of life.

We raise these troubling facts because we believe patients, families and health care professionals together must make better decisions about treatment near the end of life. We must learn to ask difficult questions, such as: can we afford to spend \$10,000 dollars a day on treatment that only prolongs dying in the ICU?

When is another round of chemotherapy for cancer, another surgical intervention or another round of antibiotics for infection simply too expensive for the lack of benefit it brings to the patient? Facing such troubling questions is not easy.

We hope that the information in this handout will help you discuss these issues directly with the physicians and nurses treating you or your loved one. Good communication is so important. It can help alleviate some of the stresses and burdens of serious illness, especially when the patient is entering the final chapter of life.

Palliative Care for pain and suffering

Pain and other types of suffering are a terrible burden for both the patient and their family. Your primary health care team may call on specialists in palliative medicine and/or pain management to help lessen the burdens of serious illness.

Palliative Care focuses on relieving many of the physical, emotional, social and spiritual symptoms related to advanced illness, death and dying. A team of caregivers, including physicians, nurses, pharmacists, social workers, chaplains, occupational therapists, child-life specialists, speech therapists, nutritionists and others make up the Palliative Care team.

Working together, their goals are to:

- relieve symptoms and improve the patient's quality of life;
- assist the patient's loved ones in coping with illness; and
- assist the primary physician and other members of the primary health care team to best serve the patient and family.

WHO IS ELIGIBLE FOR PALLIATIVE CARE?

Any patient with a life-limiting illness is potentially eligible for palliative-care assistance. The patient may or may not be considered terminally or irreversibly ill. Please see the "Definitions" section in the last part of this handout for an explanation about "terminal" and "irreversible" illnesses.

WHAT'S THE DIFFERENCE BETWEEN PALLIATIVE CARE, HOSPICE CARE AND PAIN MANAGEMENT?

While there is some overlap in the three types of care, there are also distinct differences.

- Palliative Care patients may or may not be terminally ill and may continue to receive aggressive, life-sustaining treatments.

- Hospice patients must be terminally ill and must stop all aggressive, life-sustaining treatments. For some patients who do not respond to attempts at cure or ongoing aggressive life-sustaining treatment, Palliative Care may become a “bridge to hospice.”
- Pain management consults focus almost exclusively on reducing physical pain, primarily through medical procedures. Patients with life-limiting illnesses often have a lot of troubling symptoms beyond physical pain. The Palliative Care team may assist in alleviating the symptoms.

WHAT SERVICES DOES A PALLIATIVE CARE CONSULTATION PROVIDE?

A Palliative Care consultation can provide comfort and assistance to patients and their families for a number of their needs. Depending on the patient's circumstances, they can:

- help manage physical symptoms such as pain, shortness of breath, nausea and fatigue;
- help manage depression, grief and anxiety;
- provide emotional, psychological and spiritual support for the patient, family and primary team;
- help children face the death of a family member;
- provide counseling related to a patient's prognosis and decisions near the end of life;
- assist with advance care planning such as Living Wills;
- provide guidance when you need to name a person who will make decisions for you when you are no longer able to make your own decisions;
- provide guidance on practical matters such as insurance, finances or arranging medical equipment;
- help coordinate care with physicians, home or hospice care, nursing homes or extended care facilities; and
- provide grief counseling and bereavement support.

Other services you may need

ETHICS CONSULTATION

An ethics consultation is designed primarily to help patients, families and health care teams make difficult moral decisions. On occasion, ethics consultation is used to help resolve conflicts within families or treatment teams, or between families and treatment teams that may occur in the setting of serious illness. Unlike Palliative Care consultants, ethics consultants do not write orders or otherwise actively manage patients. All Baylor Scott & White Health hospitals have an ethics committee that can provide ethics consultation services when you request them.

ADVANCE DIRECTIVE

An advance directive is a legal document that sets out 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: Directive to Physicians and Family or Surrogates (Living Will); Medical Power of Attorney (designating someone to make medical treatment decisions for you when you are unable), and Out-of-Hospital Do-Not-Resuscitate Order.

To learn more about advance directives, please ask a member of your health care team for our informational publications “Advance Care Planning” or “Simplified Advance Care Plan and Living Will (Optional)” or you may visit our Web site at www.BSWHealth.com/PatientInformation.

Conclusion

At some point, almost all of us must face hard choices about treatment when cure is no longer possible. We hope the information we have provided here will help you and your family better understand this difficult time of life. It is our sincere belief that better understanding will improve your treatment, enhance communication among everyone involved, and reduce stress for all.

Definitions

The following terms frequently come up in the setting of serious illness.

ALLOW NATURAL DEATH (AND) AND DO-NOT-ATTEMPT-RESUSCITATION (DNAR) ORDERS

This is an order to not attempt cardiopulmonary resuscitation (CPR). It is typically written when CPR is known to be ineffective, when a patient is terminally or irreversibly ill, or when a patient requests that CPR be withheld. Such an order does not mean that your health care provider may avoid or not treat other problems when it is medically appropriate to provide such treatment.

ARTIFICIAL NUTRITION AND HYDRATION (ANH)

If a patient is unable to take food or liquid by mouth, or if a patient is unable to digest food well, ANH may be used. ANH may be provided by one or more of the following methods:

- **Gastrointestinal nutrition and hydration**

This method is used for patients who are unable to swallow but able to digest. Liquid nutrients are given through a variety of tubes inserted into the stomach of the patient. A tube may be inserted through the nose into the stomach. This is called a nasogastric tube and is used only for short periods of time. Sometimes the tube is surgically inserted through the abdomen into the stomach. This is often called a G-tube, J-tube or PEG tube. Nutrition provided by these tubes is sometimes called “tube feeding,” although if you tasted it, you would not likely consider it food at all! Nutrition provided in this way can be quite effective. In some illnesses it can help maintain life for years.

- **Intravenous (IV) nutrition and hydration**

IV solutions are used to provide fluid, vitamins, electrolytes like sodium or potassium, and medication. A small tube is inserted into a peripheral vein, typically in the arm. However, this method does not provide enough calories to prevent malnutrition from happening in a short period of time.

- **Total parenteral nutrition (TPN)**

TPN is a special IV solution containing enough vitamins, minerals and calories to sustain life and prevent malnutrition. This technique requires a special IV line placed in a large central vein.

Each form of ANH has benefits, burdens and risks. In many cases, ANH is life saving and helps restore health. But it can sometimes cause discomfort, and the patient may be restrained to prevent removal of the tubes or IV lines. In some cases, ANH may unintentionally hasten death.

For further information, your physician, nurse or nutritionist can provide you with a Baylor Scott & White informational handout on Artificial Nutrition and Hydration, or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on “Artificial Nutrition and Hydration”.

ARTIFICIAL VENTILATION TECHNIQUES

Machines that assist or control breathing are called mechanical ventilators. After the event that caused the breathing problems, most patients can be weaned (slowly withdrawn) from the need for ventilator assistance. Other patients, however, with an incurable illness, may remain dependent on a ventilator and would die without its support. In these cases the patient (if able), patient’s health care decision maker and doctor will need to make decisions about how long to keep the patient on the ventilator.

AUTOPSY

Autopsy means “see for yourself”. It is a surgical procedure performed after death by a medical specialist known as a pathologist. The main purpose is to learn the truth about the cause of death. Autopsies also provide knowledge to advance medical science so that other patients may benefit in the future.

For more information on autopsies, ask your physician, nurse or chaplain for the Baylor Scott & White informational handouts, or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on “Autopsy”.

BREATHING TUBES AND TRACHEOTOMIES

A tube is inserted into the lungs for artificial ventilation to take place for any length of time. An endotracheal tube is a tube inserted through the nose or mouth into the windpipe. This technique is used only for short time periods, usually a few days or weeks.

If artificial ventilation is necessary for more than a few weeks, a tracheotomy is often necessary. A tracheotomy is an incision through the neck into the trachea (windpipe) into which a tube is inserted. The tube can be used for both artificial ventilation and to suction fluids that might interfere with breathing.

CARDIAC ASSIST DEVICES

Devices such as ventricular assist devices, artificial hearts or intra- aortic balloon pumps can be used to temporarily “take over” heart function.

CARDIOPULMONARY RESUSCITATION (CPR)

When a person’s heart stops beating (cardiac arrest), CPR may be started in an attempt to get the heart beating again. It generally consists of rapid, strong pushing down on the chest, placing a breathing tube in the windpipe, intravenous medications and electrical shocks of the heart. On television, three out of four CPRs are successful. In real life, the overall chance of survival to discharge is only about one out of six in most cases. This varies with patient age and underlying condition. CPR is most effective when death is unexpected and least effective when death is expected, such as with a terminal illness. Decisions about whether or not to attempt CPR are based upon:

- the patient’s current condition;
- the odds of immediate success;
- the hope of eventual discharge from the hospital in satisfactory condition; and
- patient preferences.

For further information on CPR, your physician, nurse or social worker can provide you with a copy of the Baylor Scott & White informational handout on Cardiopulmonary Resuscitation, or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on “CPR”.

DECISION-MAKING CAPACITY

The ability to understand information and make important decisions is vital for patients. Decision-making capacity includes (1) the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment and (2) the ability to reach an informed

decision on the matter. Caregivers may measure a patient’s decision-making ability in these ways:

- the ability to communicate dependably with caregivers, either with words or with some sign;
- the ability to understand important information; and
- the ability to understand the situation and its consequences related to his or her personal values and goals.

DIALYSIS (KIDNEY DIALYSIS)

The kidneys are essential for getting rid of waste products and making sure that the body is in chemical and fluid balance. Artificial kidney techniques such as hemodialysis or peritoneal dialysis can be used during kidney failure. Kidney failure may be temporary or permanent. These artificial kidney techniques can effectively continue life until the kidneys begin to function again or until it is determined that a transplant (if appropriate) or ongoing dialysis is needed.

HEALTH CARE DECISION MAKER, SURROGATE OR AGENT

A health care decision maker (also known as a surrogate or agent) is a person chosen to make decisions with the health care team for a patient who is no longer able to make his or her wishes known. A health care decision maker may be legally documented with a Medical Power of Attorney or in a Living Will. If a patient does not choose a health care decision maker, state law provides direction for certain persons to act on the patient’s behalf. In adult medicine, a health care decision maker is asked to make decisions based upon the patient’s values and wishes, if known. In neonatal or pediatric medicine, a health care decision maker is asked to make decisions based upon the “best interests” of the child.

HOSPICE

No matter the location, the primary goal of hospice treatment is comfort and emotional support for the dying patient, his or her family and significant others. The control of pain and other symptoms, both physical and psychological, is the primary concern. For further information about hospice, visit our Web site at www.BSWHealth.com/PatientInformation and click on “Hospice.”

IRREVERSIBLE ILLNESS

An irreversible condition is defined in Texas law as a condition, injury or illness that 1) may be treated, but can never be cured or eliminated, 2) leaves the person unable to care for or make decisions for him or herself; and 3) without life sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.

Many severe illnesses such as cancer, failure of major organs (kidney, heart, liver, or lung) and severe brain diseases such as Alzheimer's dementia may be considered incurable early on, although there can be some treatments that slow down the disease and temporarily lengthen life. Late in the course of the same illness, however, the disease may be considered irreversible under Texas law. This occurs when the patient is no longer able to make decisions or care for him or herself, but the patient may be kept alive for a long time in this condition before ultimately dying. Another example of an irreversible illness is the "vegetative state." Patients may exist in an unconscious vegetative state for years and years before death. These patients are confined to bed and sustained by a tube implanted in the stomach to deliver artificial nutrition.

LIVING WILL

A Living Will (Directive to Physicians and Family or Surrogates) is a legal document that allows the patient to state basic goals for medical treatment and the intensity of medical treatment at a time in the future when the patient 1) is no longer able to make his or her wishes known and 2) a physician has certified that the patient is terminally or irreversibly ill. Texas has one of the most patient-friendly Living Wills in the country. It offers two basic goals and treatment preferences in the setting of either a terminal or irreversible illness.

A patient may express his or her desire for either:

- aggressive treatment to attempt to maintain life in the terminal or irreversible condition as long as possible before dying (this may cause suffering), or
- comfort treatment only, allowing as gentle and peaceful a death as possible.

You may obtain a Living Will form by asking your physician, nurse, social worker or chaplain or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on "Advance Care Planning".

MEDICAL POWER OF ATTORNEY (MPA)

An MPA is a powerful legal document that allows the patient to name a person to serve as his or her health care decision maker. This person may make a broad range of health care decisions when the patient is mentally incapacitated and unable to participate in medical decisions. These decisions may include decisions to accept or reject life-sustaining treatment, whether or not the patient is irreversibly or terminally ill. It is very important that the person named as an agent under the MPA be reliable and familiar with the patient's goals and values.

You may obtain a Medical Power of Attorney form by asking your physician, nurse, social worker or chaplain or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on "Medical Power of Attorney".

ORGAN AND TISSUE DONATION

We encourage everyone to consider giving the gift of life through organ and/or tissue donation at the time of death. When a patient dies who is a potential donor, the family will be approached with the opportunity to donate organs and/or tissue as appropriate. Making a decision in advance may be comforting to all. More information on organ and tissue donation is available from your physician, nurse, chaplain, social worker, or you may visit our Web site at www.BSWHealth.com/PatientInformation and click "register online to be an organ donor".

OUT-OF-HOSPITAL DO-NOT-RESUSCITATE (DNR) ORDER

Inappropriate or unwanted CPR when you are an inpatient in the hospital is prevented when the physician writes an Allow Natural Death or DNR order. In the nursing home, home care, hospital outpatient department or other non-hospital setting, an Out-of-Hospital DNR order must be completed

to prevent emergency medical personnel from attempting 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 for patients with a terminal or irreversible illness.

PALLIATIVE CARE FOR PAIN AND SUFFERING

Palliative treatments focus on relief of pain and other suffering. Regardless of the intensity or goals of treatment, patients at Baylor Scott & White Health hospitals will receive medical and nursing care necessary to prevent suffering. Some patients may be seen by the Palliative Care Consultation Service—a specialized multidisciplinary service focusing on the unique needs of patients and families facing advanced life-limiting illnesses. Palliative Care is not hospice but sometimes serves as a bridge to hospice. Whether or not the Palliative Care service is involved in the treatment and care of a patient, when aggressive treatments are withdrawn near the end of life, we never withdraw our care. This “comfort care only” approach to medical treatment is sometimes best for a patient with a terminal, irreversible, incurable or overwhelming illness.

For more information on Palliative Care, ask your physician, nurse, social worker or chaplain for the Baylor Scott & White informational handout on Palliative Care, or you may visit our Web site at www.BSWHealth.com/Specialities and click on “Palliative Care”. You may also download an information handout at www.BSWHealth.com/PatientInformation by clicking on “Palliative Care”.

SERIOUS BRAIN INJURIES

A variety of serious brain injuries may appear superficially similar but are in fact quite different.

- **Coma:** Coma is best thought of as “eyes-closed unconsciousness.” The patient is unaware of surrounding events, has no conscious response to stimulation and no voluntary control of body movement or activity. The comatose patient feels no pain or discomfort, and the patient’s eyes are closed. Comatose patients may be kept alive with artificial ventilation, artificial nutrition and artificial hydration while awaiting determination of their final status. Many patients recover from

coma and the level of recovery may range from completely normal to partial injury (such as paralysis) or persistent vegetative state (see definition below). Some comatose patients will not recover and may worsen to the point of total absence of brain function. This is called brain death (see definition below).

- **Brain Death:** Brain death is defined as the complete absence of all brain activity. It may be observed and documented by a variety of methods. When this happens, the patient cannot recover and is medically and legally dead even though the heart is still beating. Artificial organ support such as breathing machines or IV fluids are not maintained long term once brain death is declared. Vital organs may be donated to help save the lives of others.
- **Persistent or permanent vegetative state (PVS):** The vegetative state is best thought of as “eyes open unconsciousness.” The patient’s eyes may open and close, the patient may have normal sleep/wake cycles, and the patient may have reflex body movements. But even when the patient appears awake, there is no evidence of purposeful movement or response to the environment. Depending on how long a patient is in the vegetative state, they may be classified as persistent or permanent. Patients in the vegetative state usually do not need artificial ventilation assistance. They may require artificial nutrition and hydration if it is believed the patient would wish to be kept alive in such circumstances.

For further information on severe brain injuries, your physician, nurse or social worker can provide you with a copy of the Baylor Scott & White informational handout on Serious Brain Injuries, or you may visit our Web site at www.BSWHealth.com/PatientInformation and click on “Severe Brain Injury”.

TERMINAL ILLNESS

For purposes of Texas law, a terminal condition is defined 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. However, they may not be considered terminal until the disease is fairly advanced. Patients may live with an incurable illness for many years before it becomes terminal. Remember that even if an illness has reached a terminal stage, the patient and physician will make decisions together. A Living Will only becomes active when the patient is no longer able to communicate and is terminally or irreversibly ill.

References

¹ The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*. 1995;274(20): 1591-1598.

² Wennberg JE, Fisher ES, et al. *BMJ*, March 13, 2004, Volume 328, accessed online at www.bmj.com.

³ 2003 CMS statistics and Last Year of Life study from www.cms.hhs.gov