
CONFRONTING DECISIONS ABOUT DEATH AND LIFE SUPPORT

Today I have life, how long will it last -
The days go so quickly, the months pass so fast.
My death I don't fear, but how *will* I die? Will I recognize loved ones as they bid me "good-bye?"
Please, let us talk now and make plans that are real, put them in writing so you'll know how I feel.
It's my life, you know, and I want to make sure if my last illness is serious, and there is no cure,
You'll carry out my wishes, and know in your heart, that I am at peace, and with dignity depart.

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This booklet is dedicated to all patients and families who have had to make difficult decisions about death and life support.

We gratefully acknowledge the vision, creativity, and hard work of Clara Jean Ersöz, M.D., M.S.H.A, who, while Vice President of Medical Affairs at St. Clair Hospital, authored Editions 1, 2, and 3 of this booklet. Editions 4 and 5 are revised and updated versions of her original work.

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The objectives of this publication are to address the issues regarding a patient's rights to choose medical treatments and to make decisions concerning such measures as life-support, cardiac resuscitation, and artificial feeding. Much of the information contained herein is based on the 1983 report of the President's Commission entitled "Deciding to Forego Life-Sustaining Treatment", the 1990 Commonwealth of Pennsylvania's Living Will Law and the 1998 Commonwealth of Pennsylvania, Department of Public Welfare, Medical Assistance Bulletin. Although confronting these issues can be troubling, patients and families can learn to frankly discuss their concerns and openly express their feelings before encountering the need to make these kinds of difficult decisions.

INTRODUCTION

With each advance in medical technology comes heightened expectations of longer life. Death, however, is inevitable and planning for it is critical. What kind of treatment we choose and how we and our families respond to life-threatening situations should be discussed and planned. "Death with dignity" is a right of the patient; some believe that medical technology in certain circumstances acts to distort this right. The conflict between "death with dignity" and medical technology has prompted health care professionals to encourage patients and families to confront these issues. This booklet is designed to assist families with their discussions and deliberations and then to help them document their decisions.

For ease of review, the material is divided into the following sections:

- I. **BACKGROUND** - Explains the historical basis of the problem.
- II. **COMMONWEALTH OF PENNSYLVANIA LAW** - Explains the Commonwealth of Pennsylvania's law and differentiates between a medical_living will and a healthcare power of attorney.
- III. **ST. CLAIR HOSPITAL POLICIES** - Explains St. Clair Hospital's current policies.
- IV. **GLOSSARY** - Provides an alphabetic dictionary of terms.
- V. **BIBLIOGRAPHY** - Lists pertinent articles.

I. BACKGROUND

Until the twentieth century, the use of medicines and machines to prolong life was virtually unknown. Physicians had few effective therapies from which to choose. Prior to the discovery of antibiotics, infectious disease was the leading cause of death. Heart disease, cancer and trauma are now the major causes of death. Treatments have become much more sophisticated and much medical care has moved from the home to the hospital. Within the hospital, modern medicine and technology offer a broad spectrum of treatment choices. Decisions concerning life-sustaining treatments have become increasingly complex for patients, physicians and families.

In an effort to clarify the decision-making process relative to life-sustaining treatment and the definition of death, President Carter in January 1980, established the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission was to report on the matter of defining death and to study the principles of decision-making in health care and questions of equity in the allocation of often-scarce resources. The Commission's report, *Deciding to Forego Life Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions*, was completed in December 1982.

The issues addressed in the Commission's report are complex. The conclusions of the Commission's report form part of the basis for this document which has been developed to assist patients, families and physicians with the process of making life-support treatment decisions.

Only a competent and informed adult patient or, if the patient is incompetent, an appropriately informed person acting on the patient's behalf, can make such decisions about life support. The Commission recommends that "to protect the interests of patients who have insufficient capacity to make particular decisions and to ensure their well-being and self-determination, an appropriate surrogate, ordinarily a family member, should be named to make decisions for such patients. The decisions of surrogates should, when possible, attempt to replicate the ones that the patient would make if capable to do so."

II. COMMONWEALTH OF PENNSYLVANIA

In Pennsylvania, competent adults generally have the right to decide if they want to accept, reject, or discontinue medical care and treatment. The physician is responsible for informing the patient about the risks, benefits, possible side effects, and alternatives to proposed treatments, including surgery.

An adult is considered incompetent when he or she lacks sufficient capacity to make or communicate decisions concerning him or herself. The law allows the patient's physician to decide competency for the purposes of implementing a medical living will.

MEDICAL LIVING WILL (also called "ADVANCE HEALTHCARE DIRECTIVE ")

A medical living will in Pennsylvania is a written document that describes the type of life sustaining treatment a person wants to have if the person is later incompetent and unable to discuss treatment options with the physician. In Pennsylvania, the instructions in the medical living will must relate to situations where treatment would serve only to prolong the process of dying or to maintain the person in a state of permanent unconsciousness. The Pennsylvania law requires the physician to document the patient's incompetence as well as the end-stage medical condition or state of permanent unconsciousness before a medical living will can be considered applicable. Any competent person who is at least 18 years old or is a high school graduate or who has married can make a medical living will.

HEALTHCARE POWER OF ATTORNEY

A power of attorney for health care is a document that allows you to appoint another person to act as your 'agent' to make health care decisions for you if you are unable to make these decisions yourself. With the healthcare power of attorney you can authorize your appointee to consent to your admission to health care facilities, consent to medical and surgical treatments, and manage financial and other decisions. The medical living will only allows for decisions about life-sustaining treatment.

Many documents combine features of both the medical living will and the healthcare power of attorney into a single document.

Before you complete any document you should have open discussions about your instructions with your physician, members of your family, and your clergy. This booklet identifies several issues you might consider reviewing.

If your physician or other provider is unable to honor your wishes expressed in your medical living will, the physician or other provider must help you find another physician or provider who is willing to carry out your directions, if the directions are considered valid in Pennsylvania. Pennsylvania does not generally permit a physician to honor the medical living will of a pregnant patient if the medical living will directs that the patient not be kept alive with life-sustaining treatment. There are exceptions to this requirement which can be discussed with your physician.

There is no requirement that a person have either a medical living will or a healthcare power of attorney. If you do not have such a document or agreement with another, the physician or other health care provider may ask your family or the courts to make decisions about your care for you if you are, or become, unable to make or communicate your own decisions.

Whether you do or do not wish to complete a medical living will and healthcare power of attorney for health care decisions, it is advisable to begin discussions of your wishes with your doctor and with your family (or close friends). The information in this booklet can help you initiate discussions.

III. ST. CLAIR HOSPITAL LIFE SUPPORT POLICIES

Every patient admitted to St. Clair Hospital will receive total life-support treatment unless the physician orders otherwise. "Total support" means that if the patient's vital organs fail, all treatments available at St. Clair Hospital will be used to sustain life. Life support includes such measures as admission to a critical (intensive) care unit, cardiopulmonary (heart/lung) resuscitation (also known as CPR), the use of artificial ventilation, and the use of an artificial kidney machine (dialysis).

On occasion, however, because of the nature of the illness or condition, and in conjunction with the patient and/or family, the physician(s) may order the limitation of life-support measures. There are two categories of limited life-support measures designated as "All but CPR" and "No Extraordinary Measures".

The designation "All but CPR" means that all life support measures described above are to be used to sustain life except for the use of CPR (cardiopulmonary resuscitation). In this "All but CPR" life support designation, if the patient sustains cardiopulmonary arrest (a stopping of the patient's heartbeat and/or breathing), no treatment is applied to reverse these problems and the patient will die.

After a discussion with their physician, patients may include with their "code status", specific directions regarding the use of a defibrillator or breathing tube. A defibrillator is a device, which will provide a mild shock to the heart if the patient were to exhibit a lethal rhythm. A breathing tube may be used alone or with a mechanical ventilator. The tube is usually inserted through the mouth or nose to the windpipe and makes it physically impossible for the patient to speak. The mechanical ventilator will assume the work of breathing until the patient becomes more stable. Patients may choose to include these treatments in their care or specify with their physician that they do not wish to be treated with these devices.

Patients in terminal stages of disease may receive, after careful consideration, a care classification of "No Extraordinary Measures," a classification sometimes called "Comfort Care Only" in other health care institutions. Care in this category is designed to relieve suffering and make the patient as comfortable as possible using medications, supportive nursing care, and other measures intended to relieve pain and suffering. A patient, or a person acting on the patient's behalf, who selects this care category believes that life support devices and cardiopulmonary resuscitation will only prolong death and suffering.

It is the attending physician's responsibility to inform, and to discuss treatment options with, the patient and family so that appropriate treatment categories can be chosen upon admission to the hospital or changed, as necessary, during the patient's hospital stay. Life-support treatment categories can be changed by the patient, or by the person responsible for the patient, making a request to the attending physician. A home care agency, a nursing home or any other patient care entity will be informed of the patient's and family's decisions if the patient and/or family so desire.

When a patient with a life support classification of either "All but CPR" or "No Extraordinary Measures" needs an invasive procedure and/or anesthesia for the relief of discomfort, the doctor will once again review with the patient, or person responsible for the patient, the decision about life support. This process allows for a change to a different "code status" and/or, if desired, the temporary use of the "Full Code" status for the duration of the procedure or the anesthesia.

In addition to life-support policies, St. Clair Hospital has policies that address the definition of death. "Brain death" is legally defined in the Commonwealth of Pennsylvania as the "total and irreversible end of all functions of the brain and brain stem". This clarification has become necessary as a result of our achieving the technical ability to sustain a patient's heartbeat and breathing at a time when the brain is no longer capable of being or becoming a functioning organ.

One of the most difficult decision-making situations occurs when the patient is living in a permanently vegetative state. Such a patient, despite permanent loss of consciousness, does not demonstrate all of the criteria that fully defines "brain death" and can be maintained with, and sometimes even without, sophisticated life-support systems for months and even years.

A patient's desires should be frankly discussed with family members, clergy, and friends long before the onset of any illness that might impair the patient's decision-making abilities. Such dialogue is the most sensible way to prepare for the possibility of having to make difficult decisions in the future. If you wish, you may use the information in this booklet to begin such a dialogue with family and friends and to start the preparation of a medical living will that will meet the requirements of Pennsylvania law.

IV. GLOSSARY

ARTIFICIAL KIDNEY TECHNIQUES (DIALYSIS)

Artificial kidney techniques support the patient during kidney failure. The kidneys are essential to eliminate waste products and ensure the body is in chemical balance. Kidney failure is either reversible or irreversible. In either case, artificial kidney techniques can effectively sustain life until acute kidney failure is resolved or it is determined that the patient requires chronic dialysis or kidney transplantation.

ARTIFICIAL VENTILATION TECHNIQUES

Machines called ventilators can assist a patient's breathing. These machines can either assist or control breathing depending on the physician's orders. After critical event(s), which cause breathing failures, most patients can be weaned from the need for ventilator assistance. Some patients, however, become totally dependent upon breathing assistance and without continuous ventilator support will die. Other patients become only partially ventilator dependent. When a patient remains either partially or totally ventilator dependent, the patient (if capable), family members, friends, and physician(s) may address the issues of continuation of such support and the role of CPR and other forms of life support if the patient's condition does not improve.

BREATHING TUBES

In order for artificial ventilation to be accomplished, a tube must be inserted through the patient's nose or mouth into the windpipe, the patient's main airway. This technique is a short-term alternative. While the patient requires the breathing tube, he will be unable to speak. Nursing personnel can assist patients with communication, by providing writing materials and signing boards. If long-term artificial ventilation is required, a tracheotomy tube may be necessary. A tracheotomy is an incision through the neck into the trachea (windpipe), into which a tube is inserted. Breathing tubes can be used for both artificial ventilation and removal of secretions. Special tracheotomy tubes and valves can permit speaking if the patient does not require a ventilator.

CARDIOPULMONARY RESUSCITATION (CPR)

In the early 1960's, research demonstrated that circulation of blood could be maintained in patients without a heartbeat by external cardiac (heart) massage, that mouth-to-mouth breathing was an effective substitute for breathing, and that electrical shock to the heart and special medications could reverse abnormal heart rhythms. These techniques were initially used in postsurgical recovery rooms. CPR was originally developed to treat previously healthy persons who had sustained a catastrophic event causing heart and breathing failure following surgery or a heart attack where the patient's heart was considered "too good to die." CPR was not developed as an attempt to prolong the dying of a terminally ill patient.

CPR consists of external compressions upon the breastbone (sternum) above the heart, artificial breathing through a tube inserted into the windpipe, intravenous administration of medication, electrical shocks to the heart and, on occasion, insertion of a pacemaker for the heart.

The success rate of in-hospital CPR is variously reported but the long-term survival rate after cardiopulmonary arrest in a general hospital population ranges from 4 to 30 percent.

Cardiac arrest occurs in the dying process of every person. Without a heartbeat, a person will die within a very few minutes. Irreversible brain damage occurs after about four minutes without blood delivering oxygen. If CPR is to be effective, it must be started immediately. Decisions about the advisability of instituting CPR must be made before the need arises. Patients, family, and physicians should generally review these matters and make decisions based on the patient's underlying condition, the likely benefit to the patient from CPR, the probability of successful resuscitation, and the hope of eventual discharge of the patient from the hospital in satisfactory condition.

FEEDING TECHNIQUES (OTHER THAN ORAL)

When a patient is unable to take food or food products by mouth, or when the patient's gastrointestinal system is unable to process food or food products, the patient may receive nutrition by one or more of the following techniques:

INTRAVENOUS

Intravenous solutions are used to provide fluid, vitamins, electrolytes and medication to a patient. An intravenous catheter is inserted into a vein usually in the hand or arm. The amount of calories that can be administered by a simple intravenous line is insufficient to effectively sustain life for long periods.

TOTAL PARENTERAL NUTRITION (T.P.N.)

T.P.N. is a special intravenous solution containing vitamins, minerals and adequate calories to sustain life. This technique is generally used in those situations where the patient cannot take food by mouth and the gastrointestinal tract is unable to process food or food products. This technique requires a special intravenous line.

ENTERAL FEEDING

Liquid food can be administered through a variety of tubes inserted into the gastrointestinal tract (stomach) of patients who can digest the food. A nasogastric or feeding tube may be inserted through the nose into the stomach. If long-term artificial feeding is anticipated, a gastrostomy or jejunostomy tube is favored. These tubes, inserted into the stomach or intestine, require an operation or special procedure for insertion but are good long-term alternatives and more comfortable for the patient.

Recent court decisions have reviewed the question of discontinuation of feeding by feeding techniques other than oral. In order to remove feeding tubes, the courts are looking for a clear expression on the part of the patient concerning his or her wishes regarding discontinuation of feeding. The patient and his/her chosen surrogates should carry out a frank discussion of this matter. The attached durable power of attorney form deals with matters of "artificial feeding."

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