

## Appendix A

### Glossary of Terms About End-of-life Decision Making

**Advance directive** - A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

**Artificial nutrition and hydration** – Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein.

**Assisted Suicide** - Providing someone the means to commit suicide, such as a supply of drugs or a weapon, knowing the person will use these to end his or her life.

**Best Interest** - In the context of refusal of medical treatment or end-of-life court opinions, a standard for making health care decisions based on what others believe to be "best" for a patient by weighing the benefits and the burdens of continuing, withholding or withdrawing treatment.

**Brain Death** -The irreversible loss of all brain function. Most states legally define death to include brain death.

**Capacity** - In relation to end-of-life decision-making, a patient has medical decision making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

**Cardiopulmonary Resuscitation** - Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

**Do-Not-Resuscitate (DNR) order** - A DNR order is a physician's written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

**Emergency Medical Services (EMS)**: A group of governmental and private agencies that provide emergency care, usually to persons outside of health care facilities; EMS personnel generally include paramedics, first responders and other ambulance crew.

**Euthanasia** - The term traditionally has been used to refer to the hastening of a suffering person's death or "mercy killing". Voluntary active euthanasia involves an intervention requested by a competent individual that is administered to that person to cause death, for example, if a physician gives a lethal injection with the patient's full informed consent. Involuntary or non-voluntary active euthanasia involves a physician engaging in an act to end a patient's life without that patient's full informed consent. See also Physician-hastened Death (sometimes referred to as Physician-assisted Suicide).

**Guardian ad litem** - Someone appointed by the court to represent the interests of a minor or incompetent person in a legal proceeding.

**Healthcare Agent:** The person named in an advance directive or as permitted under state law to make healthcare decisions on behalf of a person who is no longer able to make medical decisions.

**Hospice care** - A program model for delivering palliative care to individuals who are in the final stages of terminal illness. In addition to providing palliative care and personal support to the patient, hospice includes support for the patient's family while the patient is dying, as well as support to the family during their bereavement.

**Incapacity** - A lack of physical or mental abilities that results in a person's inability to manage his or her own personal care, property or finances; a lack of ability to understand one's actions when making a will or other legal document.

**Incompetent** - Referring to a person who is not able to manage his/her affairs due to mental deficiency (lack of I.Q., deterioration, illness or psychosis) or sometimes physical disability. Being incompetent can be the basis for appointment of a guardian or conservator.

**Intubation** - Refers to "endotracheal intubation" the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

**Life-Sustaining Treatment** - Treatments (medical procedures) that replace or support an essential bodily function (may also be called life support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and certain other treatments.

**Living Will** - A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a "directive to physicians", "health care declaration," or "medical directive." The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatments to delay death.

**Mechanical ventilation** - Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease.

**Medical power of attorney** - A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a health care proxy, durable power of attorney for health care or appointment of a health care agent. The person appointed may be called a health care agent, surrogate, attorney-in-fact or proxy.

**Palliative care** - A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, by controlling pain and symptoms, and by enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values are an essential component. Palliative care is sometimes called "comfort care" or "hospice type care."

**Power of Attorney** - A legal document allowing one person to act in a legal matter on another's behalf pursuant to financial or real estate transactions.

**Respiratory Arrest:** The cessation of breathing - an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating, resulting in cardiac arrest.

**Surrogate Decision-Making** - Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

**Ventilator** - A Ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

**Withholding or withdrawing treatment** - Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.

## Terms You Should Understand

1. **Artificially provided fluids and nutrition:** The provision of food and water to seriously ill patients who are unable or unwilling to eat. Depending on the method used, such as insertion of a feeding tube or an intravenous line, the condition of the patient, techniques may involve minor surgery, continuous supervision by medical (and sometimes surgical) personnel, risk of injury or infection, and side effects.
2. **Cardiopulmonary Resuscitation (CPR):** A treatment administered by health care professionals when a person's heartbeat and breathing stops. CPR may restore functioning if administered properly and in a timely fashion and may include the use of mechanical devices and/or drugs.
3. **Life-sustaining measures:** Any medical procedure, device, artificially provided fluids and nutrition, drugs, surgery, or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, thereby prolonging the life of a patient.
4. **Decisionmaking capacity:** A patient's ability to understand benefits and risks of a proposed medical treatment and its alternatives and to reach an informed decision.
5. **Health care representative or health care proxy:** In the event an individual loses decisionmaking capacity, a health care representative or proxy is a person who has been legally designated to make decisions on his or her behalf. A health care representative is appointed through the execution of a proxy directive (a durable power of attorney for health care).
6. **Terminal condition:** The terminal stage of irreversibly fatal illness, disease, or condition. While determination of a specific "life expectancy" is not required for a diagnosis of a "terminal condition", a prognosis of a life expectancy of one year or less with or without the provision of life-sustaining treatment, is generally considered terminal.
7. **Permanent unconsciousness:** A medical condition defined as total and irreversible loss of consciousness. The term "permanently unconscious" includes the conditions persistent vegetative state and irreversible coma. Patients in this condition cannot interact with their surroundings or others in any way and do not experience pleasure or pain.
8. **Persistent vegetative state:** A condition of permanent unconsciousness in which the patient loses all capacity for interaction with their environment or other people. It is usually caused by an injury to the brain. It is normally not regarded as a terminal condition and with the aid of medical care and artificial fluids and nutrition patients can survive for many years.

9. ***Incurable and irreversible chronic diseases:*** Disabling diseases such as Alzheimer's disease, organic brain syndrome or other diseases, which get progressively worse over time, eventually resulting in death. Depending on the disease, the patient may also experience partial or complete loss of physical and mental abilities. Because the rate at which these diseases advance may be slow, such diseases are not considered terminal in their early stages.
10. ***Whole brain death:*** Death due to total and irreversible loss of all functions of the entire brain, including the brain stem. The criteria of whole brain death must be used to accurately determine death in individuals who have suffered massive or total brain damage but whose heart and lungs are kept functioning by machines. Brain dead individuals are not vegetative or in a coma, but are, in fact, dead.
11. ***Attending physician:*** The doctor directly responsible for your medical treatment. He or she may or may not be your regular family physician. Depending on your health care needs, the attending physician may consult with others in order to diagnose and treat your medical condition, but he or she remains directly responsible for your care.