

Glossary of Terms Related To End of Life Planning and Care

Advance care planning (ACP) is an ongoing process of discussing and clarifying the current state of a person's goals, values and preferences for future medical care. The discussion often, but not always, leads to the signing of documents known as advance directives. A health care proxy is the only advance directive authorized by Massachusetts statute.

Advance directive (AD) is a general term referring to a written document to direct future medical care in the event that a person loses capacity to make health care decisions (i.e. becomes "incapacitated."). It sometimes results from the process known as advance care planning. A health care proxy or a living will is considered to be an advance directive.

Artificial hydration and nutrition (AHN) is a medical treatment that supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and/or fluids through a tube placed directly into the digestive tract (enteral); or through a tube directly into a vein (parenteral).

Cardio-pulmonary resuscitation (CPR) is a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include pressing on the chest to mimic the heart's functions and cause blood to circulate; insertion of an airway into the mouth and throat, or insertion of a tube into the windpipe; artificial ventilation such as mouth-to-mouth or other mechanically assisted breathing; the use of drugs to stimulate the heart; and/or electric shock (defibrillation) to stimulate the heart. CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.

Comfort Care/Do Not Resuscitate Verification protocol (CC/DNR) is followed by emergency medical service (EMS) personnel when encountering an authorized CC/DNR Verification Form outside of a hospital setting. The CC/DNR protocol directs that a patient in respiratory or cardiac arrest be made as comfortable as possible, but that no resuscitative measures be attempted.

Decision-making capacity refers to the ability to make and communicate meaningful decisions based upon an understanding of the relevant information about options and consideration of the risks, benefits, and consequences of the decision. The ability to understand other unrelated concepts is not relevant. Capacity can vary according to the task: it may be possible for an individual to appoint a health care agent, for example, yet not make a decision about a medical procedure. Capacity should be assessed routinely, and it is not the same as competence, which is a legal determination made in court. In Massachusetts the determination of a patient's lack of capacity must be made by a physician in writing before a health care proxy can be put into effect.

Dialysis is the process of filtering the blood through a machine via two small tubes inserted into the body in order to remove waste products from the body in the way that the kidneys normally do. Dialysis can be done temporarily in order to allow the kidneys time to heal or it can be done on a longer term basis in order to prolong life.

Do Not Hospitalize orders (DNH) are medical orders signed by a physician, nurse practitioner or physician assistant that instruct health care providers not to transfer a patient from a setting such as a nursing facility (or one's home) to the hospital unless needed for comfort.

Do Not Intubate orders (DNI) are medical orders signed by a physician, nurse practitioner or physician assistant that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress.

Do Not Resuscitate orders (DNR) are medical orders signed by a physician, nurse practitioner or physician assistant that instruct health care providers not to attempt cardio-pulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.

Durable Power of Attorney for Health Care is a term used in some states for a health care proxy. (See definition below.)

Guardian is a court-appointed individual granted authority to make certain decisions regarding the rights of a person with a clinically diagnosed condition that results in an inability to meet essential requirements for physical health, safety or self-care. In Massachusetts not every guardian has authority to make health care decisions. If a health care proxy is in effect, a healthcare decision of the agent takes precedence over that of the guardian (absent an order of the court to the contrary). Further, guardians who do have authority to make health care decisions may be subject to limitations on their authority to make decisions regarding life-sustaining treatments.

Health care agent is a trusted person, officially appointed, who speaks on behalf of a person 18 years of age or older who is unable to make or communicate health care decisions. In Massachusetts this person is appointed in advance via a health care proxy. The agent is called upon only if the doctor determines in writing that a patient lacks capacity to make health care decisions. Unless otherwise limited by the person, the agent has all the rights that the patient has with regard to medical decision-making, including the rights to refuse treatment, to agree to treatment, or to have treatment withdrawn. Decisions should first be made based on the patient's stated wishes, if known; or if unknown, an interpretation of what the patient would have wanted; or finally, an assessment of the patient's best interest.

Health care proxy (HCP) is a document in which a person appoints a health care agent to make future medical decisions in the event that the person becomes incapacitated. This may be an outcome of the advance care planning process and is expressly authorized in Massachusetts by statute (MGL 201D).

Hospice is a philosophy of holistic end of life care and a program model for delivering comprehensive palliative care to persons who are in the advanced stages of terminal illness and their loved ones in the home or a home-like setting. Hospice provides palliative care in the last months of life. It involves a team-oriented approach that is tailored to the specific physical, psycho-social and spiritual needs of the person and includes support to the family during the dying process. Hospice also provides bereavement support after death occurs.

Life-sustaining treatment refers to medical procedures such as cardio-pulmonary resuscitation, artificial hydration and nutrition, and other medical treatments intended to prolong life by supporting an essential function of the body in order to keep a person alive when the body is not able to function on its own.

Living will (LW) is a document in which a person specifies future medical treatments in the event of incapacity, usually at end of life or if one becomes permanently unconscious, in a persistent vegetative state or "beyond reasonable hope of recovery." Since there is no statute in Massachusetts that expressly authorizes living wills they are not considered to have legal authority. They may, however, be used as evidence of a person's wishes.

Medical (or Physician's) Orders for Life-Sustaining Treatment (MOLST /POLST) is a document intended for seriously ill patients that documents decisions for life-sustaining treatment based on the patient's current condition. A MOLST form becomes effective immediately upon signing and is not dependent upon a person's loss of capacity. It does not take the place of a health care proxy. Consideration of MOLST may be an outcome of the advance care planning process.

Palliative care is a comprehensive approach to treating serious illness that focuses on the physical, psycho-social and spiritual needs of the patient. The goal of palliative care is to prevent and relieve suffering and to support the best quality of life for patients and their families through such interventions as managing pain and other uncomfortable symptoms, assisting with difficult decision-making, and providing support, regardless of whether or not a patient chooses to continue curative, aggressive medical treatment.