



Know Your Choices:

A Guide for Patients with Serious Advancing Illness

In Massachusetts, all patients with serious advancing illness have a legal right to receive information about their medical conditions, their likely outcome (“prognosis”), and their full range of options for care. This enables patients or their advocates to make informed decisions about healthcare choices that reflect each person’s goals, values, wishes, and needs. This guide outlines the types of choices that patients have when they’re going through treatment for a serious, life-limiting illness.

Although it can be difficult to think about future healthcare choices – especially when an illness is stable and symptoms are manageable – there is much wisdom in talking with your loved ones and your healthcare providers when you are feeling strong and can make your wishes clearly known. The topics described below – **Advance Care Planning, Palliative Care, Hospice Care, and Medical Orders for Life-Sustaining Treatment (MOLST)** – are important to discuss with your healthcare providers, along with your family and others in your support system.

The Massachusetts Department of Public Health created this guide to support patients and their family members with important information about healthcare choices, especially when facing a serious illness.

Advance Care Planning: Expressing Your Wishes

Advance care planning is about taking steps to make sure you get the medical care you would want if you were too sick or hurt to express your wishes, even when doctors and family members are making those decisions for you. It is important to talk with family and trusted loved ones about your goals, values and wishes for future medical care, regardless of your current health needs. And it is important for patients and their families (or advocates) to have these conversations with the patient's care providers throughout the illness, even at the beginning. Decisions that might come up include whether you want to use a breathing machine, have tube feeding, or be resuscitated if your heart stops.

Advance directives are legal documents that allow you to spell out your preferences about end-of-life care ahead of time. In Massachusetts, a Health Care Proxy is the legally accepted form of advance directive. It is a simple legal document that allows any adult to name a trusted person to make future healthcare decisions on his or her behalf if that person is ever unable to make or communicate those decisions. The designated person is known as a "health care agent." The health care agent must wait until a physician determines and documents that a patient is not able to make or communicate those decisions on his or her own.

Resources for Advance Care Planning:

Massachusetts Health Care Proxy information, instructions and form:
www.massmed.org/healthcareproxy

NIH National Institute on Aging:
www.nia.nih.gov/health/publication/advance-care-planning

The Conversation Project:
theconversationproject.org

Better Ending (includes translations of the Health Care Proxy form in Spanish and Vietnamese and audio files in English and Spanish):
www.betterending.org.

Honoring Choices, Massachusetts:
www.honoringchoicesmass.com

In order to ensure that a person's wishes for future healthcare are known and respected, it is important to complete a "Health Care Proxy" – a written record of decisions made about future medical care.

Palliative Care: Managing Symptoms

What is palliative care?

Palliative care is a team-based approach to treating serious illness that focuses on a person's physical, emotional and spiritual needs. Palliative care is appropriate for patients at any age, regardless of the expected outcome of their illness. The goal of palliative care is to prevent and relieve the physical symptoms, anxiety, and stress that often accompany a serious illness. This includes managing pain, shortness of breath, fatigue, nausea, loss of appetite, and decreased function. Palliative care services also help patients and family members with planning for future needs, coordinating care, and working through sometimes difficult decisions.

Who provides palliative care?

Palliative care is provided by a team of professionals with a variety of different skills. This team can include physicians, nurses, social workers, chaplains, and others.

Who can receive palliative care?

Anyone with a serious illness, regardless of his or her age, life expectancy or prognosis, can receive palliative care services.

Is palliative care the same as hospice?

No, but they are related. Palliative care (providing comfort and support) is a component of hospice care, but it can be delivered at any point in a serious illness – at home, hospital, etc. Hospice care is specifically about the end of life.

Where do I receive palliative care?

Palliative care can be provided anywhere, including in the hospital or at home.

Palliative means:

Soothing
Calming
Relieving

Palliative care includes:

- Physical Symptom Relief
- Coordination of Care
- Patient and Family Support
- Assistance with Decision Making

Clarifying a common misconception: Palliative care does NOT prevent other treatments from being provided, including life-prolonging or even potentially curative measures.

Does my insurance cover palliative care?

Most insurance plans, including Medicare and Medicaid, cover some medical services that are considered palliative care. This will depend on the patient's condition and where he or she is receiving care (home, hospital, etc.). For specific information about your healthcare coverage, contact your insurance plan.

May I keep my current doctor if I am receiving palliative care?

Yes! Palliative care teams work closely with a patient's primary doctor. They provide an extra layer of treatment and support.

Resources for Palliative Care:

Hospice and Palliative Care Federation of Massachusetts:
www.hospicefed.org

National Hospice and Palliative Care Organization:
www.nhpc.org

"Questions and Answers for Patients, Families, and Surrogates" from the New York State Department of Health:
www.health.ny.gov/professionals/patients/patient_rights/palliative_care/2012-06-26_proposed_questions_answers.htm

Partnership for Palliative Care:
restoringqualityoflife.org/what-is-palliative-care/palliative-care-and-insurance

Hospice Care: Managing the End of Life

What is hospice care?

Hospice care is a philosophy of end-of-life care that looks at the whole person. Hospice provides an array of comfort and support services – also called palliative care – to patients and their loved ones. This is usually when a serious illness is no longer responding to treatments focused on a cure.

Hospice helps patients who are dying clarify their priorities and establish their goals of care while providing relief from pain and other symptoms. Hospice treatments do not aim to lengthen life. Instead, they focus on ensuring comfort and dignity so that the final months of a patient's life are as meaningful and fulfilling as possible, for both the patient and family.

Who provides hospice care?

In most cases, a healthcare team manages hospice care. Doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers all provide care, each based on his or her special areas of expertise. Together they provide complete medical, emotional, and spiritual care to the person who is dying.

Who can receive hospice care?

Anyone who has received a diagnosis of a terminal illness may receive hospice care.

Where do I receive hospice care?

A terminally ill person may get hospice services wherever he or she is, including in a hospital or at home. A patient living in a nursing facility or long-term care facility can receive specialized visits from hospice nurses, home health aides, chaplains, social workers, and volunteers, in addition to other care and services offered by the nursing facility.

Hospice helps patients clarify their priorities and establish their goals of care, while providing relief from pain and other symptoms.

Clarifying a common misconception: Hospice is NOT about giving up!

Does my insurance cover hospice services?

Many insurers (including Medicare) require that an illness be considered terminal, often that life expectancy is less than six months. For specific information about your healthcare coverage, talk to your insurance plan provider.

Resources for Hospice Care:

Hospice and Palliative Care Federation of Massachusetts:
www.hospicefed.org

Hospice Foundation of America:
www.Hospicefoundation.org

Home Care Alliance of Massachusetts:
www.thinkhomecare.org

American Cancer Society:
www.cancer.org/treatment/findingandpayingfortreatment/choosingyourtreatmentteam/hospicecare/hospice-care-services

Children's Hospice and Palliative Care Coalition:
www.chpcc.org

Medical Orders for Life-Sustaining Treatment (MOLST): Communicating Your Care Choices

What is MOLST?

MOLST is a medical order form that is based on a patient's rights and preferences to accept or refuse medical treatment – including treatment that might extend the person's life. It reflects decisions made by seriously ill patients about certain medical treatments they want, or do not want, to receive. These decisions can be changed at any time, even after completing and signing a MOLST form. Using MOLST is voluntary. The MOLST form is used to communicate medical orders from a care provider (ex: doctor or nurse) to other health professionals (ex: emergency responders).

Is MOLST the same as a Health Care Proxy?

No. The MOLST form is a medical document that can be acted on immediately based on a person's current medical situation. Health Care Proxy forms are legal documents that take effect only after a person is no longer able to communicate his or her wishes.

Resources for MOLST:

Massachusetts Medical Orders for
Life Sustaining Treatment:
www.molst-ma.org