



Massachusetts Department of
Developmental Services (DDS)



Massachusetts Councils
on Aging (MCOA)



Center for Developmental Disabilities
Evaluation and Research

END OF LIFE PLANNING

In Massachusetts, the individual receiving care is at the center of all planning and is engaged as fully as possible, including the decisions surrounding end of life (EOL) care.

The [DDS Policy on Life Sustaining Treatment](#) guides EOL planning. At the heart of the policy is informed decision making that upholds the individual's dignity, comfort and quality of life in accordance with their wishes.

Informed consent is required for important decisions, such as financial, medical, and EOL care.

Guardianship is a legal status determined by a court. It can be limited if assistance is needed in only some areas, such as finances; and must be expanded to consent to end of life decisions.

A **legally competent** individual may name a **health care agent (HCA)** to act for them if they become incapacitated. This can happen even before a serious illness. That agent is named in the Health Care Proxy document.

For an individual facing a life-threatening condition, Massachusetts has a medical form that indicates the individual's treatment preferences. It's called the MOLST, which stands for [Massachusetts Medical Orders on Life Sustaining Treatment](#). It's a medical order issued by a health care provider. It is placed in the medical record. It's issued only when there is a terminal or life threatening condition.



Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders are part of the MOLST. The individual (or their guardian) and their health care provider sign the MOLST. If the individual is incapable, the court may expand the HCA or guardian's authority to do so. An involved family member may also sign it without court permission.

If the individual is expected to live less than six months, they are eligible for **hospice**, which is provided at home, hospice house, or in a long-term care facility. Hospice will complete an assessment in order to determine if a person is eligible for hospice.

TAKE ACTION:

Well before someone receives a diagnosis of dementia, initiate informal discussions so that their wishes and preferences are known and recorded. Your Service Coordinator or Area Office Nurse can help direct you to legal and end of life planning resources.

Advance Directive

- DDS recommends [Five Wishes](#), an advance directive, which guides the discussion and records the person's wishes for their end of life experience. It is not a medical order, but it is part of the person's record. Ideally it's written with family or friends well before a serious illness. It's a helpful tool for discussing difficult end of life topics, and considers wishes about treatment and comfort, funeral arrangements, and how a person wishes to be remembered. Service Coordinators and Area Office Nurses have Five Wishes forms available.

Guardianship

- If a person is unable to make important decisions, speak to your Service Coordinator about putting a guardian in place. If the person already has a guardian, discuss whether or not the guardianship needs to be expanded for end of life decisions. Click the link for information on [Guardianship](#).

Health Care Agent

- Speak to a Service Coordinator to get advice on completing the legal document known as a **Health Care Proxy (HCP)**, which names the HCA.

End of life health care planning

- Discuss with the primary care physician, whether a MOLST is appropriate. If so, put one in place. Notify the Area Office if a MOLST is under consideration.
- Case managers, medical providers and Area Office Nurses can discuss end of life care options, including hospice and palliative care. This care is covered by [MassHealth](#) (800.841.2900 | TTY 800.497.4648)

Other Useful Links

- Find your Service Coordinator or Area Office Nurse through your [Area Office DDS Family Support Services](#) or call Department of Developmental Services **617.727.5608** | TTY **617.727.9842**
- [Aging with Intellectual and Developmental Disability series](#), which includes webinars on Aging and End of Life Planning, including Five Wishes and MOLST
- In addition to the Service Coordinator, you can get assistance through [MassOptions](#) or call **1.844.422.6277**