Life Sustaining Treatment Policy

Prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER) on behalf of the Massachusetts

Department of Developmental Services (DDS)





Massachusetts DDS Position on End of Life

- * Dignity, comfort, quality of life
- Same rights and decisionmaking options
- * Whether or not there's a guardian or health care agent







Key Principles

Informed Choice

Goals of Care

Dignity and Comfort

Use of Hospice

Use of Ethics Committees

Long Term Life Support Technology

Withholding or Withdrawing Nutrition and Hydration

Do Not Resuscitate Orders





Informed Choice



- Decisions about Life Sustaining Treatment (LST) require informed consent.
- Someone with no guardian, whose ability to make informed decisions is questioned, should be assessed by a clinical team.
- Even a court appointed guardian does not have the legal authority to make most LST decisions without expanded authority from probate court.
- Consult with the Regional Attorney in both cases.

Goals of Care



Key Points

 When, in the opinion of the medical providers, the burdens of treating a condition outweigh the benefits for the patient, treatment can shift to comfort care.

Dignity and Comfort: Palliative Care and Hospice



Key Points

In a palliative care and hospice environment:

- Comfort measures and counseling will be provided to the person and to their family and caregivers.
- Pain relief will be given, even if other treatment for the underlying condition is stopped.

Use of Hospice Care as Treatment Choice



- Hospice is an option if death expected within 6 months.
- Hospice services can be provided at home, long-term care facility, or day program.
- Hospice is a treatment option if no other treatment is viable.
- Physician must order hospice.

Use of Ethics Committees



- An ethics committee (EC) consult is helpful when there is disagreement to accept or refuse LST.
- An EC may include physicians, nurses, social workers, ethicists.
- EC opinions are advisory only.
- Where court approval for a decision is required, that decision may not be shifted to a committee.
- Substituted judgment decisions are made in consultation with the Regional Attorney.

Long-Term Life Supporting Technology



- Where there's expectation of a cure or remission of a condition, then life support measures should be taken.
- Stopping life support would be considered if the "burdens of treatment outweigh the benefits".

Withholding or Withdrawing Nutrition or Hydration



- Usually artificial nutrition and hydration are expected to be given through IV or feeding tube.
- This is determined on a case by case basis.

Do Not Resuscitate (DNR) Orders: Who May Consent?



- A legally competent person in collaboration with their qualified health care provider can consent to a DNR.
- If the person is incapable of giving consent, in some cases consent may be given by a guardian or health care agent, however;
- Consultation with the DDS
 Regional Attorney is required to determine legal authority of the guardian or agent.

Standards for a DNR Order



Key Points

In order to put a DNR in place, one or more of the conditions must exist:

- Life threatening illness or injury
- Chronic progressive disease
- Dementia
- Serious chronic health condition that requires or will require advanced medical intervention
- Any "advanced" debilitating disease

Any end of life or DNR order must be reviewed annually at the ISP.

MOLST: Who Can Consent?



Key Points

Medical Orders for Life Sustaining Treatment (MOLST) must be signed by:

- A medical doctor, physician assistant, or nurse practitioner
- The individual, if competent and capable
- The guardian, if legally authorized to do so, or the health care agent if the health care proxy has been activated

The Regional Attorney should be consulted anytime a guardian signs or if there are questions about someone's authority to sign on the person's behalf.

When to Consider a MOLST



- MOLST may only be used for a seriously ill person, and is based on the the person's wishes based on their current condition.
- MOLST becomes effective as soon as the person or their health care agent signs it.
- If a health care agent signs a MOLST it must be consistent with that person's authority as specified in the health care proxy.

Additional Webinars

- * Guardianship and Aging in Intellectual Disability, Part I & Guardianship and Aging in Intellectual Disability, Case Studies Part II
- Life Sustaining Treatment Policy
- * Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST)
- * End of Life Definitions





Additional Resources

Massachusetts Department of Developmental Services (DDS) www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html

Center for Developmental Disabilities Evaluation & Research http://shriver.umassmed.edu/cdder/aging_idd_education





Training produced by the Center for Developmental Disabilities Evaluation & Research (CDDER)

on behalf of the

Massachusetts Department of Developmental Services (DDS)



