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POLICY TITLE: Life Sustaining Treatment
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I. Policy Statement

Individuals with intellectual disability or developmental disability are entitled to express their preferences to receive or refuse medical treatment: that is, they are entitled to the same rights and decision-making options that are available regarding end of life care as the rest of society. This includes individuals under guardianship and/or with health care proxies. In Massachusetts, if an individual has been determined to lack the capacity to make informed decisions about life sustaining treatment he or she is provided with access to a substituted judgment determination by the Probate and Family Court.

II. Scope of Policy

This Policy applies to the Department of Developmental Services (“the department”) and all providers licensed or operated by the department as defined in 115 CMR 2.01.

III. Definitions of Terms:

Adult: A person who has achieved the age of maturity as specified by law, i.e. 18 years old or older.

Advanced Directives: Instructions created by a person for health care providers or the health care agent that describe the person’s wishes regarding end-of-life decisions.

Clinical Team Report (“CTR”): A medical document required by the court to establish the need for a guardian for a person with intellectual disability. The CTR must be completed by three different clinicians: a licensed psychologist, a licensed social worker and a registered physician each of whom is experienced in the evaluation of a person with intellectual

disability. Each clinician must have conducted an examination of the person to be placed under guardianship within 180 days of the filing of the CTR with the court.

Cardiopulmonary Resuscitation ("CPR"): 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 and includes cardiac compression, artificial ventilation, oropharyngeal airway ("OPA") insertion, advanced, airway management such as endotracheal intubation, cardiac resuscitation drugs, defibrillation and related procedures.

Competent: The mental capacity to make a particular decision or perform a particular act. There is a legal presumption that all individuals 18 years of age or older are competent to make decisions about their own personal and financial matters unless adjudicated incompetent to make certain (or all) decisions.

Comfort Care: Medical and nursing care that is focused on relieving symptoms and optimizing patient comfort. Comfort care does not seek to cure or aggressively treat illness or disease.

Do Not Intubate Order ("DNI"): A medical order approved by a physician, with informed consent of a competent individual, authorized health care agent or duly authorized guardian, that instructs health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress. The DNI is placed in the medical record indicating that the individual shall not be intubated. The DNI does not prohibit the treating clinicians from providing chest compressions and cardiac medication but no breathing tube will be placed. A DNI is a separate order from a Do Not Resuscitate Order (DNR); however, many times a DNI is issued along with a DNR in which case all resuscitation efforts would be withheld. **See also DNR and MOLST**

Do Not Resuscitate Order ("DNR"): A medical order signed by a physician, nurse practitioner or physician's assistant, with informed consent of a competent individual, authorized health care agent, or duly authorized guardian, that instructs health care providers not to attempt cardio-pulmonary resuscitation ("CPR") in the event of cardiac and respiratory arrest. The DNR is placed in the medical record indicating that the individual will not receive CPR if he or she experiences respiratory or cardiac arrest. A DNR does not prohibit treating clinicians from providing other treatments such as for relief of pain or respiratory distress. The DNR is only one component of defining the appropriate intensity of care, consistent with the goals of care.

Health Care Agent (HCA): The Health Care Agent (the "Agent") is the adult authorized by a competent adult ("the principal") to make health care decisions on behalf of the principal to the extent set forth in the Health Care Proxy. ("In the event the principal becomes unable to make such a decision him or herself. The authority of the Agent shall begin after a determination, in writing, by the attending physician that the principal lacks the capacity to make or to communicate health care decisions"). (See cite and definition of Health Care Proxy below).

Health Care Proxy: ("HCP") The written document (authorized by MGL c. 201D) by which a competent adult (the "principal") designates another adult as his or her "health care agent" to make or communicate health care decisions when the principal becomes unable to make a decision him or herself. An individual must be "of sound mind and under no constraint or undue influence" to appoint a health care agent.

Hospice care: Medical/nursing services, emotional support, and spiritual resources for people who are in the last stages of a serious illness. Hospice care also helps family members and others supporting the individual manage the practical details and emotional challenges of caring for a dying loved one.

Informed Consent: The type of agreement between an individual, guardian or health care agent, and physician that is required before treatment can be administered. To be informed consent, it must a) be from a legally and functionally competent authorized individual; b) include all the material facts about the proposed treatment including benefits and possible risks, and c) be given freely without coercion or undue influence.

Legal guardian: A person who has been appointed by a court of law to make legal decisions for another person who. A guardian's authority may be expanded to include the authority to make end-of-life treatment decisions, by obtaining a substituted judgment determination from the court. See also "substituted judgment."

Life Sustaining Treatment (LST): Any treatment choice having some reasonable expectation of effecting a permanent or temporary cure or remission of illness or condition being treated.

Long Term, Life-Supporting Technology: Technology used to sustain essential bodily functions on a long term basis. Examples include ventilators, dialysis, pacemakers, implanted defibrillators and transplantation.

Medical Orders for Life Sustaining Treatment (MOLST) Form: MOLST forms are statewide standardized forms issued by the Massachusetts Department of Public Health, which patients and their health care providers can use to document the results of discussions they have had regarding appropriate life-sustaining treatment to assure that a person with valid end of life medical orders are treated in accordance with those orders. A MOLST is a medical order.

Palliative care: Care that is focused on alleviation of pain, improving life and providing comfort to people with serious, chronic, and life-threatening illnesses—but also anyone who is ill and experiencing pain may be referred to palliative care for pain management .

Substituted Judgment: A process used by a probate court to make certain decisions on behalf of an individual who is incapable of making an informed decision where neither guardian nor health care agent is authorized to do so. The court dons the "mental mantle" of the individual to make decisions the individual would make if he/she were competent. (Note: A Health Care Agent may make all health care decisions, including substituted judgment type, without court involvement, if authorized by the HCP.)

In a substituted judgment, the court tries to put itself into the shoes of the individual and make the decisions the individual would make if he or she were competent. Typically, a court will consider the following factors to arrive at a determination of what an individual would choose:

1. The individual's expressed preference (if any);
2. The existence of the individual's religious convictions, if any, and their relation to acceptance or refusal of treatment;
3. the impact on the family insofar as this factor would affect the individual's choice;
4. the probability of adverse side effects; and
5. the prognosis both with and without treatment.

These factors help the court to determine what the individual would want if he or she were competent. However, the court also considers other factors in reaching a final decision. These include: the State's interest in the preservation of life and the prevention of suicide (duty to prolong life); the protection of the interests of innocent third parties; and the integrity of the medical profession (i.e., professional ethics and sound medical practice).

Withholding or withdrawing of treatment: The decision to stop a treatment already underway is called "withdrawing treatment." The decision not to start a treatment is called "withholding treatment." There is no a legal distinction between withholding and withdrawing treatment.

IV. Principles of Policy

A. Informed Choice

In addition to equal rights to treatment or to refuse treatment, LST decisions must be shown to be based on the criteria of informed choice, avoidance of harm and benefit to the individual of the proposed treatment. A determination must be made as to whether the individual is competent to make an informed life sustaining treatment decision. For a person under guardianship, the guardian may or may not have the authority to consent to or refuse LST. For someone not under guardianship, the lack of a guardian is not dispositive of the individual's capacity to make a LST decision. In either circumstance, there should be consultation with the Regional Attorney for the purpose of reviewing the guardianship decree and determining the scope of the guardian's authority to accept or refuse LST, or to determine whether a guardian should be appointed to accept or refuse LST when an individual is facing such a decision to ensure that the decision is based upon informed choice. In cases that an individual has been determined to lack capacity to make informed decisions about LST and there is no other authorized individual to make those decisions, the court will determine what the individual's substituted judgment would be. The goal is to provide an incapacitated individual the equal right to choose or refuse treatment. *See* Section V, Substituted Judgment).

B. Goals of Care

A determination to redirect the goals of care from cure to comfort may be made when the benefits of continued attempts to achieve a cure or prolong life, from the individual's perspective, no longer exceed the burdens imposed by those attempts. This generally, arises in the context of a terminal condition, although it may involve individuals with progressive illnesses.

C. Dignity and Comfort—palliative care and hospice

When the goals of care have changed from a cure to comfort, the use of palliative or comfort care measures should be considered. Hospice care emphasizes comfort measures and counseling to provide social, spiritual, and physical support to the dying patient, his or her family, and surrogate caregivers. To preserve the dignity and comfort of an individual, treatment for relief of pain will be given even if treatment for the underlying condition is withheld or withdrawn.

D. Use of hospice care as a treatment choice

The diagnosis of a terminal condition resulting in death within six (6) months is the major criterion by which a patient is eligible for hospice care. Hospice services may be provided in the home as well as in long- term care facilities. Hospice care may be a valid "treatment

choice” if no other treatment is considered viable or is recommended by the treating physician. A hospice agency may be consulted to determine if an individual is eligible for hospice services.

E. Use of Ethics Committees

When there is a difference of opinion regarding the decision to accept or to refuse LST, or to consent to a DNR, it may be useful to obtain an ethics committee consult to ensure that the human rights and dignity of the individual have been fully considered. Where court approval of a decision is required, the ultimate decision-making responsibility may not be shifted away from the courts to any committee, panel or group, ad hoc or permanent. A decision whether a substituted judgment is required for a LST decision must be made in consultation with the Regional Attorney.

F. Long Term Life Supporting Technology

There is an expectation in favor of life supporting technology where treatment has some reasonable expectation of effecting cure or remission of the illness being treated. When the burdens outweigh its benefits, the treatment is no longer compatible with the goals of care.

G. Withholding or Withdrawing Nutrition and Hydration

There is an expectation in favor of nutrition and hydration through traditional and artificial means but there is no legal presumption that such treatment must be provided. Decisions to withhold or withdraw nutrition and hydration are decided on a case by case basis.

H. Do Not Resuscitate Orders

A Do Not Resuscitate Order (DNR) may be appropriate for an individual under certain circumstances.

1. Who May Consent to a DNR?

A legally competent individual, in collaboration with his or her physician or other qualified health care provider (physician, physician assistant, or nurse practitioner) may consent to a DNR order. Where an individual is found not capable of giving informed consent, in certain circumstances, consent may be given by the guardian or HCA. In all cases involving LST orders, consultation with a Regional Attorney is required to verify the legal surrogate’s legal status with respect to the authority to consent to medical decision-making.

2. Standards for Do Not Resuscitate (DNR) Orders

In order for a DNR Orders to be consistent with this Policy, one or more of the following conditions or health states must exist:

- Life threatening illness or injury
- Chronic progressive disease
- Dementia
- Serious chronic health condition that requires or will require advanced medical interventions
- Any “advanced” debilitating disease process

End-of-life or DNR orders for individuals under care of the DDS shall be reviewed at least annually at the ISP for determination of continued appropriateness.

I. MOLST Orders

1. Who Can Consent to a MOLST?

A MOLST form must be signed by a physician, physician assistant or nurse practitioner, and the individual (patient), or, in cases that the individual has a health care proxy (HCP) that has been activated, by the health care agent (HCA) or by a guardian with legal authority to do so. It is the responsibility of the signing clinician to know if the patient has capacity to sign the MOLST form. If the patient's decision-making capacity is uncertain, the signing clinician should seek clinical counsel.

The Regional Attorney should be consulted anytime a MOLST form signed by a guardian is presented to DDS or if there are questions about someone's authority to make MOLST decisions or to sign a MOLST on the patient's behalf. *See also* Section IV. H., above, Do Not Resuscitate Order.

2. When Should a MOLST Be Considered?

A MOLST is a medical order and may *only* be used for a seriously ill patient. A MOLST stipulates wishes for life-sustaining treatment based on the patient's current condition. Based on an individual's current medical condition, the categories on the MOLST form specify an individual's wishes with respect to end-of-life orders. A MOLST shall not be executed for someone who is not seriously ill or near end-of-life. A MOLST becomes effective immediately upon signing and is not dependent upon a person's lack of capacity.

3. MOLSTs and Health Care Proxies

When a Health Care Agent has signed a MOLST on behalf of a Principal, the consents must be consistent with the health care agent's authority as set forth in the Health Care Proxy document.

For more specific operations details please refer to the Life Sustaining Treatment (LST) Case Referral Protocol.