

OFFICIAL POLICY

DEPARTMENT OF DEVELOPMENTAL
SERVICES



POLICY TITLE: Goals of Care for Life-Limiting Illness
POLICY NUMBER: 2024-01 (replaces former Policy #2017-1)
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COMMISSIONER'S SIGNATURE: Jane F. Ryder, Commissioner
Jane F. Ryder

Individuals with intellectual or developmental disability, autism, acquired brain injury, and other disabilities supported by the Moving Forward Plan (MFP) waivers are entitled to express their preferences to receive or decline 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.

Medical treatment decisions aimed at what to do if an individual experiences a medical emergency must be shown to be based on the criteria of informed choice, avoidance of harm and benefit to the individual.

Individuals with serious life-limiting conditions who have capacity to make their own decisions can choose to change their code status: that is, they can choose to be full code, elect to be "do not resuscitate, intubate only," or "do not resuscitate and do not intubate." Regardless of determinations of legal capacity, the expressed preferences of the individual should always be considered when decisions are being made regarding their care. A change in code status does not prohibit treating clinicians from providing other treatments such as antibiotics, hospitalization, or relief of pain or respiratory distress. The code status is only one component of defining the appropriate intensity of care, consistent with the goals of care.

Those with serious life-limiting conditions who have capacity to make their own decisions may choose to be seen for palliative care. Palliative care focuses on alleviation of pain, improving quality of life and providing support to people with serious, chronic, and life-threatening illnesses. Palliative care is provided alongside disease-directed or curative treatment and should be offered to individuals with serious illness, alongside other treatment(s) for their condition. When the goals of care change from curative to comfort, the use of comfort care measures should be considered. If someone chooses comfort measures, they can still receive other treatments, such as those that provide pain and anxiety management. An individual who chooses "comfort measures only" may still choose medications, such as antibiotics, cardiac/seizure medications, and continuation of tube feeds, if they feel these treatments align with their goals of care.

Hospice is the standard of care and should be offered to individuals at the stage of a life-limiting illness when further curative treatment is not available or recommended by the treating physician.

When there is a difference of opinion or ethical concern regarding the decision to receive or decline life-sustaining treatment such as cardiopulmonary resuscitation or intubation, DDS may choose to consult with an ethicist or an ethics committee to aid in the decision. Where court approval of a decision is required, the ultimate decision-making responsibility may not be shifted away from the court to any committee, panel, or group.

A legally competent individual, in collaboration with a qualified health care provider (physician, physician assistant, or nurse practitioner) may consent to a change in their code status. When an individual is found not capable of giving informed consent, in certain circumstances consent may be given by the guardian or Health Care Agent with proper legal authority.

One or more of the following conditions must be present in order for a change in code status to be consistent with this Policy:

- 1) Life threatening illness or injury
- 2) Chronic progressive disease
- 3) Dementia
- 4) Serious chronic health condition that requires or will require advanced medical interventions
- 5) Any advanced debilitating disease process
- 6) Extreme progressive frailty that is not responding to medical treatment

Code status orders for all individuals under the care of DDS shall be reviewed annually by the DDS team supporting the individual in order to determine continued compliance with this policy.