

**CHAPTER 48B****DECISION-MAKING FOR THE TERMINALLY ILL****Authority**

N.J.S.A. 26:2H-53 et seq. and 26:6A-1 et seq.

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**Chapter Expiration Date**

Chapter 48B, Decision-Making for the Terminally Ill, expires on November 3, 2008.

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**SUBCHAPTER 1. GENERAL PRINCIPLES****10:48B-1.1 General principles**

(a) Staff of the Division shall be guided by the following principles with respect to decision-making for the terminally ill:

1. Concerning ethical issues:

i. The provision of appropriate end-of-life treatment for terminally ill individuals with developmental disabilities can raise some special ethical concerns. This is particularly the case for individuals with developmental disabilities who are receiving services from the State of New Jersey. On the one hand, the State has a special responsibility to protect individuals with developmental disabilities from all forms of discrimination, including medical treatment discrimination, based solely on the presence of a developmental disability. On the other hand, individuals with developmental disabilities who are terminally ill should not be subjected to medical interventions at the end-of-life simply because the State wishes to avoid the appearance of discrimination, that is, a perception that medical interventions are being withheld solely because of an individual's disabilities. Persons with developmental disabilities, as any other citizen, have the right to receive quality palliative care and the right to refuse medical treatment.

ii. Medical ethics has created a patient-centered framework for weighing the ethical obligation to provide interventions vs. the ethical decision to withhold and/or withdraw medical interventions. This framework identifies five major elements:

- (1) The effectiveness of treatment;
- (2) The benefit of the treatment;
- (3) The burden of the treatment;
- (4) The ratio of benefit to burden; and
- (5) An understanding of the wishes, values and goals expressed by the individual or a surrogate acting on his or her behalf.

iii. To the extent possible, individuals with developmental disabilities who are receiving services from the State of New Jersey should receive the highest quality end-of-life care. Individuals acting on their behalf should seek to weigh the benefits and burdens of treatment in considering the best interest of the individual, that is, they should strive to avoid under-treatment, as well as over-treatment at the end of life. Finally, in all instances, they should make every effort to protect and nourish the dignity of individuals with developmental disabilities confronting terminal illnesses.

## 2. Concerning palliative care:

i. Individuals with developmental disabilities who are terminally ill should have access to the highest quality of palliative care. Palliative care encompasses a comprehensive approach to meeting the multi-dimensional needs of terminally ill individuals. It includes the provision of the appropriate medical, emotional, physical, psychosocial and spiritual support and care for the terminally ill individual.

ii. A special dimension of a palliative care program is the provision of appropriate medications and therapies designed to alleviate the pain and suffering of the terminally ill individual. The provision of appropriate pain management for individuals with developmental disabilities who are terminally ill presents some special challenges because often the individual may be unable to adequately express the severity and locus of pain and suffering. Therefore, particular attention needs to be paid to this aspect of end-of-life care by health care professionals who are trained to meet this need.

iii. In some instances, individuals with developmental disabilities who are terminally ill may benefit from a hospice program capable of providing comprehensive end-of-life care. Terminally ill individuals should have access to hospice care whenever appropriate. A hospice program may be provided in virtually any type of living arrangement, including, but not limited to, a health care facility specifically designed for hospice care, in a hospital, in a long-term health care facility, in a developmental center, in a community residence as defined in N.J.A.C. 10:44A or 10:44B, or in a private home.

iv. Good end-of-life care for terminally ill individuals often requires the administration of care in a setting familiar to the individual. This can contribute immensely to the emotional and psychological wellbeing of the individual. Accordingly, the Division will seek to utilize generic and specialized resources towards providing appropriate hospice care to terminally ill individuals within developmental centers and community residences in New Jersey.

“Advance directive” means a written document executed in accordance with the requirements of the New Jersey Advance Directive for Health Care Act, N.J.S.A. 26:2H-53 et seq. It is a written instruction stating the individual’s general treatment philosophy and objectives, and/or the individual’s specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life sustaining medical treatment. It may also be used for the individual to name a health care representative to make medical decisions on behalf of the individual, if he or she loses capacity.

“Attending physician” means the physician selected by, or assigned to, the individual who has primary responsibility for the treatment and care of the individual.

“Bureau of Guardianship Services (BGS)” means the unit within the Division of Developmental Disabilities which has the responsibility and authority to provide guardianship of the person to individuals in need of such services (N.J.A.C. 10:45-1.2).

“Capacity” means an individual’s ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision on his or her own behalf. An individual’s decision-making capacity is evaluated relative to the demands of a particular health care decision.

“Do Not Resuscitate (DNR) Order” means a physician’s written order not to attempt cardiopulmonary resuscitation in a hospital or out-of-hospital situation in the event the individual suffers cardiac or respiratory arrest.

“Emergency care” means immediate treatment provided to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

“Ethics Committee” means a multi-disciplinary standing committee, which shall be designated by the Division Director or his or her designee pursuant to N.J.A.C. 10:48B-3.1 and shall have a consultative role, when the Bureau of Guardianship Services (BGS) is the guardian, in reviewing a recommendation for a “Do Not Resuscitate Order” (DNR) or for withholding or withdrawing an individual’s life-sustaining medical treatment.

“Health care facility” means a hospital, a residential health care facility or nursing home, an assisted living facility, a developmental center, or a private residential facility licensed under N.J.A.C. 10:47. Community residences licensed under N.J.A.C. 10:44A or 10:44B are not health care facilities.

## SUBCHAPTER 2. DEFINITIONS

### 10:48B-2.1 Definitions

The following words and terms, as used in this chapter, shall have the following meanings, unless the context clearly indicates otherwise: