

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

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

Source and Effective Date

R.2009 d.203, effective June 15, 2009.
See: 41 N.J.R. 845(a), 41 N.J.R. 2480(a).

Chapter Expiration Date

Chapter 48B, Decision-Making for the Terminally Ill, expires on June 15, 2014.

Chapter Historical Note

Chapter 48B, Decision-Making for the Terminally Ill, was adopted as new rules by R.2003 d.421, effective November 3, 2003. See: 34 N.J.R. 4299(a), 35 N.J.R. 5098(a). Chapter 48B, Decision-Making for the Terminally Ill, expired on May 2, 2009. See: 41 N.J.R. 845(a).

Chapter 48B, Decision-Making for the Terminally Ill, was adopted as new rules by R.2009 d.203, effective June 15, 2009. See: Source and Effective Date. See, also, section annotations.

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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 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 medical treatment and assessment available, including 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.

3. Concerning Ethics Committees:

i. Ethics Committee members shall have knowledge, experience and/or training regarding ethical issues pertaining to end-of-life care and the unique characteristics of individuals with developmental disabilities.

Amended by R.2009 d.203, effective June 15, 2009.

See: 41 N.J.R. 845(a), 41 N.J.R. 2480(a).

In (a)liii, inserted "medical treatment and assessment available, including"; and added (a)3.

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:

"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 Department of Human Services, 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.

"Disability Rights New Jersey (DRNJ)" means the organization designated by the Governor to be the agency to implement, on behalf of the State of New Jersey, the Protection and Advocacy System established under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§15041-15045.

"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 recognized by the Assistant Com-