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*** New Jersey Register, Vol. 46 No. 11, June 2, 2014 ***

TITLE 10. HUMAN SERVICES
CHAPTER 48B. DECISION-MAKING FOR THE TERMINALLY ILL
SUBCHAPTER 2. DEFINITIONS

N.J.A.C. 10:48B-2.1 (2014)

§ 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 Commissioner of Legal, Regulatory and Guardianship Services, 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 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.

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"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.

"Hospice" means a program, which is licensed by the New Jersey Department of Health and Senior Services to provide palliative services to terminally ill individuals in the individual's home or place of residence, including medical, nursing, social work, volunteer and counseling services.

"Immediate family" means spouse, civil union partner as defined in P.L. 2006, c. 103, children, parents and siblings. Immediate family may also include individuals less closely related to the individual by blood or marriage, but who have been interested and involved with the individual's welfare.

"Life sustaining medical treatment (LSMT)" means the use of any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery, or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function and thereby increase the expected life span of the individual.

"Medically contraindicated" means that to a reasonable degree of medical certainty, CPR will be unsuccessful in restoring cardiac and respiratory function, or that the individual will experience repeated arrest in a short time period before death occurs or that CPR would impose unwarranted physical trauma on the patient in light of the individual's medical condition and the expected outcome of resuscitation for the individual.

"Palliative care" means a holistic approach to individual care, integrating medical, psychosocial, and spiritual elements, in the presence of an incurable progressive illness that is expected to end in death. Designed to decrease the severity of pain, suffering, and other distressing symptoms, palliative care recognizes that dying is part of living. Palliative care is provided to the individual, the family, and others involved in the individual's illness by an interdisciplinary healthcare team, including nurses, social workers, chaplains, and physicians. The expected outcome of palliative care is to enable the individual to experience an improved quality of life.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards, and with reasonable medical certainty, as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes, but is not limited to, a persistent vegetative state or irreversible coma.

"Regional Long Term Care Ethics Committee" means a multi-disciplinary body of individuals, at least two of whom have completed the training program sponsored by the Office of the Ombudsman for the Institutionalized Elderly. Regional Long Term Care Ethics Committees provide to the long-term care community expertise of multi-disciplinary members who offer case consultation and support to residents and health care professionals who are facing ethical dilemmas (N.J.A.C. 8:39-5). Regional Long Term Care Ethics Committees also provide education for residents and families, health care professionals and the local community (N.J.A.C. 8:39-13.4). Regional Long Term Care Ethics Committees provide policy development to enhance facilities' ethical decision-making.

"Supportive care plan" means a plan of care to be developed by the health care facility for each individual for whom a Do Not Resuscitate (DNR) Order is proposed. The plan is individualized to meet the individual's needs and shall consider fluid/intravenous therapies, nutrition, symptom management/medication, invasive diagnostic and therapeutic procedures including, but not limited to, mechanical ventilation, kidney dialysis, pulmonary, arterial or venous catheters, transfusions, laboratory, x-ray and other tests. This plan shall also include non-medical interventions that address the individual's psychosocial and spiritual needs and may include complementary therapies, such as aromatherapy, music therapy, pet therapy, and the like.

"Terminally ill individual" means an individual receiving services from the Division, who is under medical care and has reached the terminal stage of an irreversibly fatal illness, disease or condition and the prognosis of the attending physician and at least one other physician asserts that the medical prognosis indicates a life expectancy of one year or less if the irreversibly fatal illness, disease or condition continues on its normal course of progression, based upon reasonable medical certainty.

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TITLE 10. HUMAN SERVICES
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SUBCHAPTER 3. ETHICS COMMITTEES

N.J.A.C. 10:48B-3.1 (2014)

§ 10:48B-3.1 Recognition of Ethics Committees

(a) The Assistant Commissioner or his or her designee shall recognize acute care hospital Ethics Committees and standing Ethics Committees to be independent of the Division of Developmental Disabilities that shall be available for consultation to BGS whenever end-of-life decision-making issues arise.

1. An Ethics Committee, other than an acute care hospital Ethics Committee, shall assure to the Division the following:

- i. Knowledge, experience, and/or training regarding ethical issues pertaining to end-of-life care decision-making;
- ii. The ability to be available for case consultation in a prompt and expeditious manner proportionate to the urgency of the situation. An absolute minimum of three members of the Ethics Committee must be involved to provide consultation for any case regardless of the degree of urgency thereof; and
- iii. Knowledge, experience, and/or training regarding the nature and characteristics of individuals with developmental disabilities.

2. While Hospital Ethics Committees are not required to assure to (a)1 above, they are expected to meet those requirements as part of the Ethics Committee protocol.

(b) After an Ethics Committee has been recognized by the Assistant Commissioner, or his or her designee, for end-of-life consultation, the chairperson of the Ethics Committee shall assure the continuing applicability of the elements contained under (a) above.

(c) Each Ethics Committee shall include a membership of no less than five individuals optimally drawn from different disciplines. Ideally, the membership should include:

1. A non-attending physician;
2. A non-attending nurse;
3. A social worker;
4. A member of the clergy;
5. An ethicist;
6. A lawyer;
7. At least one member of the community interested in and experienced with individuals with developmental disabilities; and
8. A licensed health care professional with expertise in the medical concerns of the individual.

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SUBCHAPTER 4. DECISION-MAKING CAPACITY

N.J.A.C. 10:48B-4.1 (2014)

§ 10:48B-4.1 Determination of terminally ill individual's capacity regarding either Do Not Resuscitate (DNR) orders or the withholding or withdrawing of life-sustaining medical treatment (LSMT)

(a) It is the attending physician's role to recommend a course of treatment for a terminally ill individual or an individual in a permanently unconscious state, including a Do Not Resuscitate (DNR) Order and/or the initiation, withholding or withdrawing of life sustaining medical treatment (LSMT). In some instances, the attending physician may recommend a DNR order when the act of cardiopulmonary resuscitation is contraindicated due to the medical condition and/or age of the individual and could cause more physical harm than benefit.

(b) To the extent possible, Division staff shall provide to the attending physician any information or records pertinent to the issue of whether a terminally ill individual may or may not have the capacity to make medical treatment decisions, including documents such as a previous adjudication of incapacity or a determination by the Chief Executive Officer (CEO) of a developmental center or Regional Administrator of a Division community services office that the individual has capacity to make medical treatment decisions.

(c) If the attending physician recommends a DNR Order or the initiation, withdrawal or withholding of LSMT, the physician must determine whether the individual has the capacity to make these medical treatment decisions. In some instances the individual may not have the capacity to make major medical decisions, but may have the capacity to express some preferences about treatment options in the face of a terminal illness. The attending physician should make an effort to determine the preferences of the individual, and these should be considered in the development of the final treatment plan. If an individual who lacks decision-making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate measures utilized to sustain life be provided, that wish shall take precedence over any contrary recommendation or determination.

(d) The attending physician may consider information supplied by the Division staff BGS, or other interested persons to determine whether the terminally ill individual has the capacity to make medical decisions.

(e) The attending physician shall determine whether the patient lacks capacity to make a particular health care decision. The determinations shall be stated in writing, shall include the attending physician's opinion concerning the nature cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

(f) The attending physician's determination of a lack of decision-making capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's record in the same manner as that of the attending physician. Confirmation of a lack of decision-making capacity is not required when the patient's lack of decision-making capacity is clearly apparent, and the attending physician and the legal guardian or health care representative agree that confirmation is unnecessary.

(g) If the attending physician or the confirming physician determines that a patient lacks decision-making capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician or
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the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decision-making capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's record in the same manner as that of the attending physician.

(h) The attending physician will notify the individual, the guardian or the immediate family when the individual is determined to lack capacity to make a particular healthcare decision, the right to appeal this decision and how to appeal.

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SUBCHAPTER 5. INDIVIDUALS WITH CAPACITY TO MAKE MEDICAL DECISIONS

N.J.A.C. 10:48B-5.1 (2014)

§ 10:48B-5.1 Individuals with capacity to make medical decisions

If the attending physician has determined that a terminally ill individual has capacity to make informed major medical decisions on his or her own behalf, the individual shall make decisions regarding any proposed DNR Order and/or the withholding or withdrawing of LSMT.

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SUBCHAPTER 6. INDIVIDUALS WITHOUT CAPACITY TO MAKE MEDICAL TREATMENT DECISIONS FOR
WHOM BGS IS NOT PROVIDING GUARDIANSHIP SERVICES

N.J.A.C. 10:48B-6.1 (2014)

§ 10:48B-6.1 Individuals without capacity to make medical treatment decisions for whom BGS is not providing guardianship services

(a) If the attending physician has determined that a terminally ill individual or an individual in a permanently unconscious state, not receiving guardianship services from BGS, lacks the capacity to make major medical decisions, decision-making in regard to medical treatment shall proceed according to the following guidelines:

1. If the individual has a guardian other than BGS and is in a healthcare facility operated or funded by the Division, a DNR Order or an order for the withholding or withdrawing of LSMT may be issued upon the recommendation of the attending physician and with the consent of the private guardian. An Ethics Committee review, independent of the healthcare facility, can occur if requested by the attending physician, the legal guardian or an interested party. The head of service of the Division component responsible for the individual, or his or her designee, shall provide written notice of the entry of the order to Disabilities Rights New Jersey (DRNJ) no later than the next business day;

2. If the individual is in a health care facility not funded by the Division, decision-making regarding the issuance of a DNR Order or the withholding or withdrawing of LSMT shall be addressed in accordance with the policies, procedures, and practices of the health care facility; and

3. If it is determined and confirmed by a second physician that the individual lacks the capacity to make medical treatment decisions and the individual does not have a guardian appointed for him or her, an emergent application for the appointment of a guardian should be initiated.

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N.J.A.C. 10:48B-7.1 (2014)

§ 10:48B-7.1 Individuals without capacity to make medical treatment decisions for whom BGS is providing guardianship

If the attending physician has determined that a terminally ill individual or an individual in a permanently unconscious state for whom BGS is providing guardianship lacks the capacity to make medical decisions, and the physician is recommending the withholding or withdrawing of LSMT, the recommendation shall be referred to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

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N.J.A.C. 10:48B-7.2 (2014)

§ 10:48B-7.2 Role and functions of Ethics Committees

The Chief of BGS or his or her designee shall solicit consultation from a recognized Ethics Committee whenever consent for withholding or withdrawing LSMT is being requested by the attending physician. The Ethics Committee shall meet as soon as possible depending upon the urgency of the situation.

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N.J.A.C. 10:48B-7.3 (2014)

§ 10:48B-7.3 Withholding or withdrawing life-sustaining medical treatment (LSMT) for individuals for whom BGS is providing guardianship services

(a) The following procedures shall be followed:

1. When a recommendation to authorize the withholding or withdrawal of LSMT is received by staff of BGS, the recommendation shall be referred to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

i. In preparation for presentation of a recommendation for withholding or withdrawing LSMT to an Ethics Committee recognized by the Assistant Commissioner or his or her designee, the Chief of BGS or his or her designee shall:

(1) Request a search of the individual's records to determine whether or not an advance directive exists;

(2) Obtain a description in writing from the attending physician of the diagnosis and prognosis of the individual, which substantiates the reasonableness of withholding or withdrawing potentially LSMT based upon the finding that such treatment would be more burdensome than beneficial, and contrary to the individual's best interest;

(A) The attending physician will include in the written description specific treatment recommendations for the individual.

(3) Obtain a second opinion that confirms the individual's diagnosis and prognosis; and

(4) Develop a profile detailing the relevant factors in a consideration to withhold or withdraw potentially LSMT including, but not limited to: permanently unconscious state, uncontrolled pain, severe and permanent physical and mental deterioration, or other similar criteria.

ii. When the information under (a)1i above has been gathered, BGS will request a review by a recognized Ethics Committee. In accordance with N.J.A.C. 10:48B-3.1(a) and 7.2(a), the Ethics Committee shall have a consultative role in reviewing a request to withhold or withdraw potentially LSMT.

iii. When considering a request to withhold or withdraw potentially LSMT, the members of the Ethics Committee shall consider:

(1) The recommendation of the attending physician, including the diagnosis, prognosis and medical treatment plan for the individual;

(2) A confirmation of the diagnosis and prognosis of the individual by a second physician;

(3) The wishes of the individual as may have been expressed in an advance directive;

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- (4) The contemporaneous wishes of the individual, if available;
- (5) The benefits and burdens to the individual of initiating or continuing potentially LSMT;
- (6) The wishes of the individual's family members or other interested persons;
- (7) The "best interest" standard as applied with respect to withholding or withdrawing LSMT, excluding consideration of any pre-existing, non-terminal developmental disability, the benefits or burdens to third parties or the cost of continuing medical treatment;
- (8) Medical treatment support plan for the individual; and
- (9) Any additional information deemed relevant to the decision.

iv. The Ethics Committee shall invite the Chief of BGS or his or her designee, as well as a representative of DRNJ, to attend the meeting.

v. If a majority of the members of the Ethics Committee agree that it would be appropriate to withhold or withdraw potentially LSMT, this recommendation shall be forwarded in writing to the chief of BGS or his or her designee immediately.

vi. If a majority of the members of the Ethics Committee agree that the withholding or withdrawing of LSMT would be inappropriate, or are unable to reach a consensus, this shall be reported to the chief of BGS or his or her designee. The chief of BGS or his or her designee will make the decision as to rendering or withholding consent.

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N.J.A.C. 10:48B-7.4 (2014)

§ 10:48B-7.4 Procedures for rendering decision

(a) If the Ethics Committee recommends withholding or withdrawing of LSMT and DRNJ participates in the meeting, the Chief of BGS or his or her designee may make a decision immediately following the meeting. If the Chief of BGS or his or her designee decides to withdraw or withhold LSMT and DRNJ does not express an objection, consent can be given at that time. BGS shall prepare a certification pursuant to (b) below.

(b) If DRNJ does not participate in the Ethics Committee meeting and the Ethics Committee recommends withholding or withdrawing LSMT, and the Chief of BGS or his or her designee concurs with the recommendation, the Chief or his or her designee shall prepare a certification outlining the following:

1. The recommendation of the Ethics Committee;
2. The request of the attending physician, including a diagnosis and prognosis and a medical treatment plan;
3. A second opinion from another physician;
4. A history of individual's abilities and a progression of his or her illness;
5. The disposition of the family members, if any;
6. The BGS guardian's observations of the individual;
7. The recommended medical treatment support plan;
8. The wishes of the individual in an advanced directive, if one exists;
9. The recommendations of BGS staff; and
10. Any other information deemed relevant to the decision.

(c) The Chief of BGS or his or her designee shall forward the certification to DRNJ no later than the next business day. DRNJ shall notify BGS regarding any objection by way of a written communication no later than one business day after receipt of the certification. If DRNJ raises no objection to BGS' determination, the Chief of BGS or his or her designee shall authorize the withholding or withdrawing of LSMT.

(d) If the Chief of BGS or his or her designee disagrees with, or has questions about, a recommendation of the Ethics Committee to withhold or withdraw potentially LSMT, he or she shall request a second review by the Ethics Committee in order to discuss the issues in question. If, after the second review, the Chief of BGS or his or her designee makes the decision not to consent to the request to withhold or withdraw LSMT, the order shall not be written. The Chief of BGS or his or her designee shall state in writing the reasons why consent has been denied. Copies of this statement shall be provided to the attending physician, the Ethics Committee and DRNJ.

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(e) Any interested party may seek resolution by a court of competent jurisdiction, in the event that he or she disagrees with the decision made by the Chief of BGS or his or her designee.

(f) In the event an interested party, including the Public Advocate and/or DRNJ, objects to the decision of the Chief of BGS or his or her designee to withhold or withdraw LSMT, the decision will not be implemented without a court order.

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N.J.A.C. 10:48B-7.5 (2014)

§ 10:48B-7.5 Do Not Resuscitate (DNR) Orders for individuals receiving BGS services

(a) The following procedures shall be followed when a recommendation has been made by the attending physician to execute a DNR Order for an individual for whom BGS is providing guardianship services:

1. The attending physician will submit a written recommendation for a DNR Order indicating the diagnosis and prognosis of the individual and the benefit or not if Cardiopulmonary Resuscitation (CPR) is instituted. If the individual is not terminally ill or permanently unconscious and the attending physician is recommending that CPR is medically contraindicated for the individual, the attending physician will specify in the written recommendation the reasons CPR is contraindicated.

2. The staff of BGS will search the records for an advance directive or seek information on a contemporaneous or previously expressed wish of the individual.

3. A second treating physician will indicate in writing his or her concurrence with the attending physician's recommendation for a DNR Order.

4. The staff of BGS will contact the next of kin or interested persons to establish their perception of the individuals' wishes or what is in the best interest of the individual.

5. The Chief of BGS, or his or her designee, may request consultation by a recognized Ethics Committee if the BGS staff seeks a recommendation regarding a DNR Order request. The Ethics Committee shall consider the request in accordance with N.J.A.C. 10:48B-7.3(a)1iii, except the committee will consider a DNR request.

6. If the Chief of BGS or his or her designee concurs with the recommendation for a DNR Order, the Chief or his or her designee shall prepare a certification based upon the following:

- i. The recommendation of the attending physician, including a diagnosis, prognosis and a medical treatment plan;
- ii. The concurrence and recommendations of a second treating physician;
- iii. A brief history of the individual's abilities and description of the progression of the illness;
- iv. The disposition of any family members or interested parties;
- v. The observations by the BGS guardian of the individual;
- vi. The recommended medical treatment support plan to include hospice or palliative care, as appropriate; and
- vii. Any additional information deemed relevant to the decision.

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7. Once the certification has been completed, the Chief of BGS or his or her designee shall communicate consent to the DNR Order to the attending physician and provide DRNJ with a copy of the certification no later than the next business day.

8. If an emergent request for a DNR Order is made by the attending physician and the Chief of BGS, or his or her designee, agrees with the request and concurs that the request meets the requirements of this chapter, consent will be given to the physician to enter a DNR order.

9. The Chief of BGS, or his or her designee, will prepare a certification pursuant to (a)6 above and send a copy to DRNJ, no later than the next business day.

(b) Any interested party may seek resolution by a court of competent jurisdiction, in the event that he or she disagrees with the decision made by the Chief of BGS or his or her designee.

(c) In the event an interested party, including the Public Advocate and/or DRNJ, objects to the decision of the Chief of BGS or his or her designee to consent to DNR Order, the decision will not be implemented without a court order.

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SUBCHAPTER 8. PALLIATIVE CARE

N.J.A.C. 10:48B-8.1 (2014)

§ 10:48B-8.1 Palliative care

(a) Palliative care services, including hospice services, may be provided for an individual with a terminal or life-threatening illness. Consideration for admission into a hospice program may require that a DNR Order be in place. If so, all of the procedures for consent to a DNR Order delineated above under N.J.A.C. 10:48B-7 shall be followed prior to admission into a hospice program.

(b) Palliative care services, including hospice, may be provided in a health care facility specifically designed for hospice care, at a hospital, in a developmental center or in a community residence as defined in N.J.A.C. 10:44A or 10:44B.

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