POLICY ON HOSPICE INFORMED CONSENT

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Introduction

In New York State, only a health care proxy or a court-appointed guardian may legally provide consent to elect hospice on behalf of an incapacitated adult. However, any person who has decisional capacity, even if such capacity is apparent only in interludes, may make his/her own health care decisions, such as appointing a health care proxy.

Under the Hospice Conditions of Participation, a "representative" may consent to hospice on behalf of an individual who is physically or mentally incapacitated. 42 C.F.R. § 418.24. See Addendum A. A "representative" is defined as "an individual who has been authorized under State law to terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill individual who is mentally or physically incapacitated." 42 C.F.R. § 418.3. See Addendum B. Under New York law, there is no provision legally authorizing anyone to provide consent for an incapacitated individual who does not have a health care proxy or a legal guardian. Under New York Public Health Law § 2965, Addendum C, surrogate decision-making is permitted for Orders Not to Resuscitate ("DNR"). In the absence of a health care proxy, a surrogate may be chosen in order of priority from a spouse, a son or daughter eighteen years of age or older, a parent, a brother or sister eighteen years of age or older, and a close friend. Consent under the DNR law is expressly limited to DNRs, however, and does not extend to any other medical treatments. New York Public Health Law § 2504, Addendum D, provides for consent to be given on behalf of minors, but does not address issues of consent for incapacitated adults. New York is one of only three states that does not automatically allow those closest to an incapacitated person the right to make medical decisions for them. See Addendum E.

Under the current state of the law, we recommend that patients who have the capacity be encouraged to designate a health care proxy. Article 29-C of the Public Health Law governs health care proxies, Addendum E. There is a presumption of competence in the law. "Every adult shall be presumed competent to appoint a health care agent unless such person has been adjudged incompetent or otherwise adjudged not competent to appoint a health care agent, or unless a committee or guardian of the person has been appointed." Public Health Law §§ 2980-2981. See Addendum F.

For persons who are unconscious or so severely impaired that they lack even the limited capacity required to designate a health care proxy, there is no one legally authorized to consent to hospice unless a guardian has been appointed. There may be some evidence to help support a hospice election for patients who, prior to losing decisional capacity, have expressed their wishes to loved ones regarding end of life care. A patient may have told a family member, for example, that they do not want to be kept alive by machines in the event that they are terminally ill. Although New York has no statutory living will, the courts will enforce advance directives, whether written or oral, if they provide clear and convincing evidence of a person's wishes. See Matter of O'Connor, 72 N.Y. 2d 517 (1988) and 10 NYCRR §§ 400.21(b)(3) and 700.5 (b)(3). See Addendum G.
The process for having a guardian appointed under Article 81 of the Mental Hygiene Law is usually too costly and too time-consuming to be feasible in the hospice context.

**POLICY**

1. All patients are presumed to have capacity to make their own medical decisions unless it has been determined that they do not have such capacity. To determine whether the health care proxy has authority, *Public Health Law § 2983* governs. See Addendum E. Generally, a determination that a patient lacks capacity to make health care decisions shall be made by the attending physician in writing, stating the cause of the incapacity, and its extent and probable duration. A second physician’s opinion that the patient lacks capacity is required to permit a health care proxy to withdraw or withhold life-sustaining treatments.

If the attending physician determines that a patient in a general hospital or mental hygiene facility lacks capacity to make health care decisions because of mental illness, the attending physician must consult with a qualified psychiatrist prior to permitting the health care proxy to make these medical decisions.

If the attending physician determines that a patient lacks capacity to make health care decisions because of a developmental disability, the attending physician must consult with a physician or clinical psychologist pursuant to *Mental Hygiene Law § 81.29, Addendum H*, prior to permitting the health care proxy to make these medical decisions. The consultation must be with a physician or clinical psychologist who:

   a. Is employed by a school named in Mental Hygiene Law § 13.17; or

   b. Who has been employed for a minimum of two years to render care and services in a facility operated or licensed by the Office of Mental Retardation and Developmental Disabilities (“OMRDD”); or

   c. Who has been approved by the Commissioner of OMRDD in accordance with regulations that require the consulting physician or psychologist possess specialized training or three years’ experience in treating developmental disabilities.

   **Note:** If the attending physician is the patient’s health care proxy, he/she cannot make a decision as to the patient’s capacity. Also, if the patient objects to the incapacity determination by the physician to permit the health care proxy to make medical decisions, the patient prevails unless a court determines that the patient lacks capacity.

Any determination of incapacity should be documented in the medical record.

2. Any patient with capacity can make his/her own decisions regarding hospice care. All discussions and decisions regarding hospice care will be made with the patient unless the patient instructs High Peaks differently in writing.
3. If a patient no longer has capacity, but had elected a health care proxy when he/she did have capacity, the health care proxy may make the decision to elect hospice care for the patient.

4. If a patient does not have capacity and does not have a health care proxy but does have a guardian or legal representative, the guardian or legal representative may elect hospice care for the patient. 42 C.F.R. 418.3. See Addendum B.

5. If a patient is mentally retarded or developmentally disabled and does not have capacity but has a court-appointed guardian, the provisions set forth in the New York Surrogate’s Court Procedure Act § 1750-b and Mental Hygiene Law § 81.29 apply for hospice election. See Addendum H with cover memo from C. Raffa.

6. If a patient is not mentally retarded, does not have capacity and does not have a proxy or a legal representative, but has made statements of intent, or by actions has indicated a desire for hospice care, New York case law supports that a surrogate decision-maker may possibly elect hospice for the patient. Prior to hospice admission for any patient who meets these criteria, a referral to the Hospice Ethics Committee will be made to determine what evidence exists to determine the patient’s wishes. Note: Where hospice must rely on evidence of a patient’s actions and statements to determine his/her wishes, legal counsel should be consulted to determine whether a judicial determination is required.

7. If a patient is not mentally retarded, does not have capacity, does not have a health care proxy or legal representative, and no prior statements of intent or actions have been made regarding hospice, but the family believes that the patient should be on hospice, the case will be referred to the Hospice Ethics Committee prior to hospice admission. Note: Legal counsel should be consulted to insure there is legal authority to elect hospice. In such instances, a family member may be required to apply for a court-appointed guardianship.

8. Pursuant to 42 C.F.R. § 418.24, a patient, or his/her health care proxy, or his/her legal guardian, must sign an election statement electing hospice care. See Addendum A.

High Peaks Hospice recognizes that many patients do not have health care proxies and have not given advance directives to their relatives regarding their desire to receive hospice services. In consultation with the Hospice Ethics Committee and legal counsel, if necessary, High Peaks Hospice will make all efforts to insure that hospice-appropriate patients who are not mentally retarded or developmentally disabled, but do not have decisional capacity and lack proxies, legal guardians or advance directives, will receive the appropriate hospice care.