Decisions at Life’s End: Legal and Ethical Issues

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Tracy E. Miller, Esq
Consultant, Health and Biomedical Law
Caring for Patients at Life’s End

New York Law on Advance Planning

Advance Planning

- The Health Care Proxy
- Living Wills
- DNR Decisions
- Medical Orders for Life-Sustaining Treatment

Assessing Promise and Progress

Providing Palliative Care

Family Health Care Decisions Act
N.Y. Judicial Rulings on Treatment Decisions

Schloendorff v. New York Hospital (1914)
“Every individual of sound mind and adult years has a right to determine what shall be done with his own body.”

Previously competent 79-year old priest became permanently unconscious. Refusal of respirator allowed based on “clear and convincing evidence” of his prior wishes.

Matter of Storer (1981)
Profoundly retarded 54-year old man dying of bladder cancer. Refusal of blood transfusions denied because he had no prior wishes.

Matter of O’Connor (1988)
Demented 77-year old female patient. Refusal of feeding tube denied because no clear and convincing evidence of treatment wishes specific to her medical condition and the treatment being refused.

Fosmire v. Nicoleau (1990)
Healthy Jehovah’s Witness needed blood following C-section. Right to refuse treatment upheld, regardless of diagnosis or prognosis.
Determining Decision-Making Capacity

- All adult patients are legally presumed to have capacity to decide about treatment. **No one can make a treatment decision for an adult patient unless the patient has been determined incapable of deciding about the treatment by a court or by an appropriate process at the facility.**

- Generally encompasses ability to appreciate nature and consequences of proposed health care decision, including benefits, risks, and alternatives, and to reach an informed decision.

- Decision-specific – not all or nothing.

- Not based on status (e.g. mental illness, developmentally disabled).

- Well-documented in medical record.

- Made by a physician with appropriate expertise and consultation as needed.

- Capacity to decide about treatment distinct from capacity to sign an advance directive.
Types of Advance Directives/Decisions

- Health Care Proxy – Appoint Person to Decide
- Living Will – Specific Instructions About Treatment
- DNR Order – Advance Decision About Cardiopulmonary Resuscitation
- MOLST – Medical Orders for Life-Sustaining Treatment
Reasons to Fill Out a Health Care Proxy

- Overcome legal hurdles to forgoing treatment in New York
- Avoid conflict within the family and provide them with guidance
- Choose person most trusted or able to decide
- Empower someone outside the family to decide
- Protect decisions to stop and to accept treatment
Advance Directives

- Care providers are required to be aware of and respect patient care wishes expressed in advance directives.

- Under New York’s Health Care Proxy Law, all capable adults have the right to appoint a health care agent with legal authority to make health care decisions for the patient after the patient loses capacity. A health care agent’s decision-making authority has priority over family members or any other surrogate, regardless of their relationship to the patient.

- Adults can delegate to another person (health care agent) all or part of the adult’s authority to make health care decisions in the event s/he loses decisional capacity. Unless specifically limited in the health care proxy, the agent is authorized to make all decisions the patient could make, including decisions about life-sustaining treatment.
Advance Directives (Continued)

- A living will can be used with a health care proxy to provide the agent with additional guidance about the patient’s wishes. If a patient has specified health care instructions in a proxy form and neither the agent nor the alternate agent is available, the patient’s instructions should be honored if they provide clear and convincing evidence of the patient’s wishes.
Health Care Proxy

(1) I, ________________________________

hereby appoint ________________________________

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint ________________________________

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions): ________________________________

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (If you want to limit your agent’s authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary): ________________________________

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.
(5) **Your Identification** *(please print)*

Your Name

Your Signature _____________________________ Date _____________

Your Address ____________________________________________

(6) **Optional: Organ and/or Tissue Donation**

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs and/or tissues

☐ The following organs and/or tissues ____________________________

__________________________________________________________

☐ Limitations ______________________________________________

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____________________________ Date ________________

(7) **Statement by Witnesses** *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date __________________________________________________________________________

Name of Witness 1
*(print)* _____________________________ Date __________________________________________________________________________

Signature _____________________________ Address _____________________________

Name of Witness 2
*(print)* _____________________________ Signature _____________________________

Address _____________________________ __________________________________________________________________________
Legal Status of Living Wills in New York State

- No statute covers Living Wills (LW).
- Legal support in NYS and constitutional law if the LW provides “clear and convincing evidence” of the patient’s wishes.
- Clear and convincing evidence exists if the wishes relate to both the treatment at issue and the patient’s clinical condition.
- Clear and convincing evidence can be oral or written.
- A health care agent has authority to interpret the patient’s wishes stated in a LW or other form consistent with the primary standards under the proxy law that focus on the patient’s wishes, or if the wishes are not reasonably known, the patient’s best interests.
Legal Obligation to Provide/Honor Advance Directives

Federal Patient Self-Determination Act (1990)
All facilities must: (1) ask if patients have an advance directive, (2) inform patients of state law, (3) not discriminate against patients who exercise their rights.

NYS Health Care Proxy Law
All facilities must: (1) provide proxy on admission, (2) honor directives unless agent acting in bad faith, decisions inconsistent with standards, or validly exercised conscience objection.

Under the Proxy Law, long-term care facilities must:
(a) provide information to adult residents about their right to create a health care proxy;
(b) educate adult residents about the authority delegated under a health care proxy and how a proxy is created and revoked;
(c) help ensure that each resident who creates a proxy while residing at the facility does so voluntarily.
Decisions About Resuscitation

Overview

- Every patient is presumed to consent to the administration of CPR in the event of cardiac or respiratory arrest, unless a DNR order is written.

- A DNR order refers only to cardiopulmonary resuscitation (CPR) and does not limit any other care or treatment for the patient or authorize denial or withdrawal of treatments other than CPR.

- Under New York’s DNR law, the patient, health care agent, family members and others close to the patient, even if not appointed as agent, can decide to forgo CPR in advance, in accord with standards and process in the law.
DNR Law

- Applies in hospitals, nursing homes, mental health facilities
- Sets forth a list of surrogate decision makers
- Includes decision-making standards (terminal illness, permanent unconsciousness, futility, extraordinary burden in light of medical condition and prognosis)
- Allows orders to be transferred between facilities without a new consent
- Requires facilities to have a dispute mediation system
State of New York
Department of Health

Nonhospital Order Not to Resuscitate
(DNR Order)

Person's Name __________________________

Date of Birth __ / __ / __

Do not resuscitate the person named above.

Physician's Signature ________________
Print Name __________________________
License Number ______________________
Date __ / __ / __

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.
Barriers to Realizing Patient Autonomy

- Directive Completion Rates
- Availability of the Directives When Needed
- Concordance of Agent/Surrogate – Patient Wishes
- Physician Knowledge of Patient Wishes – Reluctance to Initiate Discussion
- Impact on Treatment Decisions
Completion Rates

- Studies in the late 1980s’ – early 1990s’
  Approximately 15% - 20% completion rate in general population
  - Support Study (Lynn et al, Journal of Clinical Ethics, 1994)
    20% (618 of 3058 patients) had completed an advance directive prior to admission

- Pew Research Study 2006 – 29% completion rate in general population compared to 12% in 1990
Long-Term Care Studies

- Staff and resident education in nursing homes – 49% completion by residents (Molloy et al., JAMA, 2000).

- Only 26% of nursing home residents with advance directives had them recognized upon transfer from the nursing home to the hospital. Morrison et al., JAMA, 1995.

- 54% of residents had completed advance directives prior to admission (Morrison et al., JAGS, 2005).
Interventions/Avenues to Improve Documentation and Recognition of Directives

1. Social work/nurse training – Long-term care study showed 47% versus 9% in control group for documented wishes about artificial nutrition and hydration and IV antibiotics (Morrison et al., 2005)

2. Electronic Medical Record

2. MOLST (Medical Orders for Life-Sustaining Treatment) or other form transferring wishes
Lack of Knowledge of Patient’s Wishes

- Patients predict that both physicians (90%) and family members (87%) would know wishes. (Seckler et al., Annals, 1991)

- Physicians have no better odds than chance alone at knowing patient wishes about life-sustaining treatments.

- Family members do not fare much better.
Communication, Conflict, Control

- Patients want to discuss advance directives with their physician, but often wait for physicians to raise the issue.
- Physicians reluctant to discuss advance directives and end-of-life choices with patients.
- Patients more likely to discuss treatment preferences with family (Pew 2006 study found 69% of those married discussed wishes with spouse compared to 51% in 1990).
- SUPPORT – physicians honored patient DNR preferences only 50% of the time.
- More recent studies – much higher concordance between patient preferences and treatments provided.
What Have We Learned?

- Advance directives a tool – a platform for discussion, but not sufficient as an end point
- There are effective ways to enhance completion and impact of the directives
- Need to shift paradigm from patient – physician relationship as locus of AD completion
- Need to focus less on specific instructions, more on goals, process of decision-making
Providing Effective Pain Relief

Untreated pain and untreated depression are leading causes of desire for suicide

Untreated or undertreated pain widespread in long-term care

Barriers to Effective Pain Relief

- Fear of liability for hastening death
- Lack of training for health care professionals
- Concerns about addiction
U.S. Supreme Court Decision


“There is no need to address the question of whether suffering patients have a constitutionally cognizable interest in obtaining relief from the suffering that they may experience in the last days of their lives. There is no dispute that dying patients in Washington and New York can obtain palliative care even when doing so would hasten their deaths.”
Legal Support for Providing Pain Medication that May Hasten Death

- Physicians do not perform euthanasia when they provide pain medication that runs the risk of hastening death, but is not intended or provided for that purpose.

- “It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient’s death, if the medication is intended to alleviate pain and severe discomfort, not to cause death, and is provided in accord with accepted medical practice.” New York State Task Force on Life and Law, *When Death Is Sought* (1994)
Guidance from the Office of Professional Medical Conduct

Obligation to Provide Pain Relief

1. Part of quality care for all patients
2. Pain should be considered a fifth vital sign and be regularly monitored
3. Controlled substances, including opioid analgesics, are essential in treating acute and chronic pain. Treatments must accord with accepted medical practice.
4. A patient who uses controlled substances for legitimate medical purposes is not an addict.
Guidance from OPMC

Regulatory Concerns

1. Inappropriate prescribing of controlled substances can lead to drug diversion and abuse by individuals who use drugs for illegitimate purposes.

2. Certain patients with pain, such as those with a history of substance abuse or co-morbid psychiatric conditions, may require extra monitoring and consultation.

3. The OPMC Board evaluates inappropriate versus appropriate prescribing, not the quantity of drugs prescribed.
Family Health Care Decisions Act

- Would apply in hospitals and nursing homes
- Replace DNR law with law covering treatment decisions for patients (adults and children) who lack capacity and have no advance directive
- Would cover all treatment decisions, not just decisions about life-sustaining measures

- Proposed in 1992
- Passed NYS Senate in July 2009
Family Health Care Decisions Act

List of Surrogate Decision-Makers

1. Guardian
2. Spouse or domestic partner
3. Adult son or daughter
4. Brother or sister
5. Close friend
Decision-Making Standard

Known wishes, or, if not known, best interests

“An assessment of the patient’s best interests shall include: consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient’s life; the preservation, improvement or restoration of the patient’s health or functioning; the relief of the patient’s suffering; and any medical condition and such other concerns and values as a reasonable person in the patient’s circumstances would wish to consider.”
Decisions to Forgo Life-Sustaining Treatment

Treatment must be an extraordinary burden and:
1. Patient is terminally ill
2. Patient is permanently unconscious; or
3. The provision of treatment would involve such pain suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances, and the patient has in irreversible or incurable condition, as determined by the attending physician with the concurrence of a second physician.

For third condition, in long-term care, ethics committee must determine the decision meets the standard.
Decisions to Provide Treatment

For Residents who Have No Surrogate:

- An attending physician is authorized to decide about routine medical treatment (for which consent is not ordinarily sought).

- For major medical treatment, the attending physician shall make a recommendation in consultation with staff directly responsible for the patient’s care; the medical director or a physician designated by the medical director must independently concur with the recommendation.

- For decisions to forgo life-sustaining treatment, a court may approve the decision to forgo treatment.
Summing Up


- Once enacted, facilities have the option to implement immediately.

- Until enacted, staff in long-term care facilities have a legal and ethical obligation to educate all residents about advance directives and explain their importance under NY law.