

# *What You Need To Know About Palliative Care and Health Care Decision Making In New York*

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# Objectives

- Health Care Decision Making in New York
- Palliative Care and Palliative Care Information Act
- What Do You Need To Talk To Your Patients About?
- Resource Information

# Some Historical Benchmarks

- 1968: Harvard criteria for brain death
- 1973: First US Hospice program
- 1975: California Natural Death Act (Living Wills)
- 1976: Quinlan case-New Jersey
- 1980s: Major cases in New Jersey, Massachusetts, New York, California
- 1983: Medicare Hospice Benefit
- 1990: Cruzan case-US Supreme Court
- 1990: Dr. Jack Kevorkian gains notoriety
- 1990s: Advance directive statutes; DPAHCs; hospital ethics committees
- 1990s: State referenda to legalize PAD; Oregon enacted in 1996 ;  
Washington enacted in 2008 on second attempt
- 2005: Schiavo case-Florida; nationwide controversy
- 2005: Legislation passed in NYS authorizing MOLST pilot
- 2008: NY Public Health Law amended authorizing MOLST in ALL settings
  
- 2010: New York Family Health Care Decisions Act and NYSDOH-5003  
MOLST Form
- 2011: New York Palliative Care Information Act

## Patients' Rights and Hospice Movements: Individual Empowerment vs. System Approaches

- Roughly the same period: first US Hospice 1973; Quinlan 1976.
- Both grassroots movements growing out of patient and family dissatisfaction with mainstream health care system.
- **Individualistic approach.** Legal empowerment to protect individual against the technological imperative. Judicial and legislative reform strategies. Institutional education and new decisionmaking mechanisms (consultation teams; ethics committees).
- **Relational approach.** The Hospice movement. Alternative model of cancer care to better meet the needs of patients and families who were being abandoned by mainstream treatment systems. Not for profit and volunteer care delivery agencies in the community. Charitable funding until creation of Medicare Hospice Benefit in 1983; increasing professionalization and business orientation since then. Parallel palliative care movement in the 1990s.

# Trends in Ethics and the Law concerning end of life care

- Growing awareness of the need for a paradigm shift in end-of-life decision making and care giving—an “individualistic paradigm” vs. a “relational paradigm”:
  - From “transactional” decision making to communicative decision making
  - From adversarial autonomy to relational values
  - From an individualistic to an ecological conception of end-of-life care

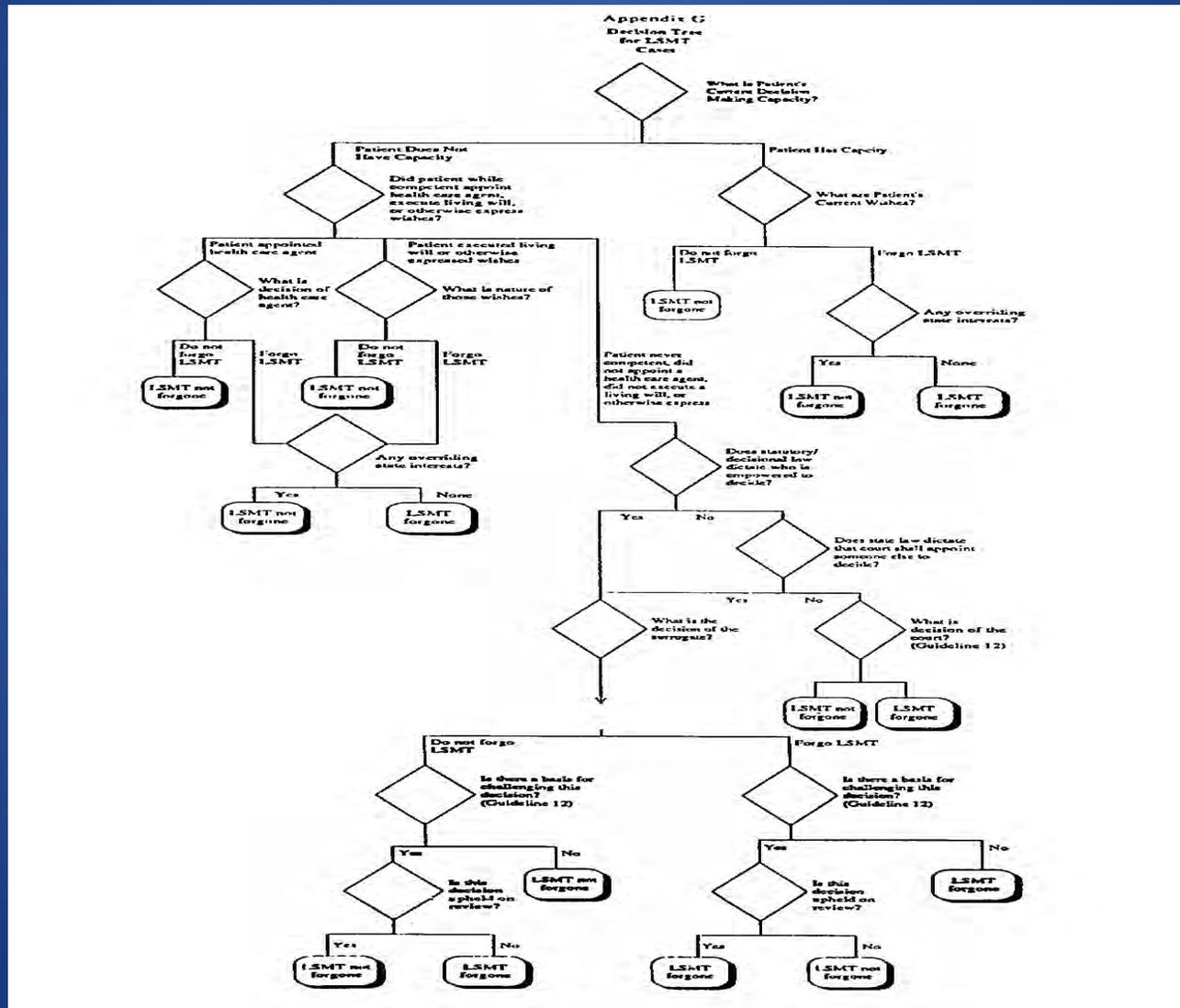
## Where are we now:

# Points of Legal and Ethical Consensus

- Patients with decision making capacity have a common law and a Constitutional right to refuse medical treatment, including life-sustaining medical treatment.
- Incapacitated patients have the same rights as patients with capacity; however, the manner in which these rights are exercised is different.
- In general, the right to refuse life-sustaining medical treatment does not depend on the patient's life expectancy. This right is not limited to those deemed to be "terminally ill."
- There is no legal or ethical difference between withholding or withdrawing life-sustaining medical treatment.
- Artificial nutrition and hydration is a medical treatment and generally may be withheld or withdrawn under the same conditions as any other form of medical treatment (Health Care Proxy law imposes limitations).
- It is acceptable to provide pain medication sufficient to control a patient's pain even if that may foreseeably hasten the patient's death.
- Active euthanasia and assisted suicide are morally and legally distinct from forgoing life-sustaining treatment. The right to refuse life-sustaining treatment does not entail the right to be assisted in committing suicide.

# Sample Decision Tree: End of Life Decisionmaking

[Source: National Center for State Courts 1993]



# Problems with the Individualistic Paradigm:

## The Burden of Advance Directives

- Emphasis on individual autonomy makes surrogate decision making problematic. The upshot is emphasis on expressions of patient preferences and values while capacitated—Advance directives and advance care planning. We have failed to integrate advance directives into more comprehensive advance care planning and case management.
- Problems:
  - Limited use of Advance Directives and difficulty implementing advance care planning.
  - Too often ADs are not done at all
  - When done, often not done well. Treatment directives are too vague. Health care agents/surrogates are not well prepared or supported in their responsibilities.
  - Even if created, advance directives are not always followed. Problems of record keeping and continuity of care (cf. later discussion of MOLST)
- Partial solution: Family Health Care Decisions Act

# Problems with the Individualistic Paradigm:

## Are quality of life judgments wrong and unjust?

- Original intent was to create a subjective, person-centered decision making process; one that is neutral and does not impose third party quality of life judgments. But is there hidden bias in the decision making process?
- Are advance directives nothing more than biased quality of life judgments imposed by a past, able-bodied self on the present, impaired self?
- Do cultural biases against dependency and impairment compromise the valid autonomy and informed consent upon which the right to refuse treatment is based?

# Core Elements of a Relational Paradigm

- Shared, informed medical decision making
- Communication that is culturally and family appropriate
- Decision making that is not ad hoc but instead centered around an advance plan
- Continuity of care across the continuum of care

## Background Assumptions of the Relational Paradigm

- Rights are relational
- Humanistic perspective: humans beings are fundamentally social and relational
- Social ecological context: nexus of social and cultural relations among human beings
- Decision making involves cognitive, affective and communicative dimensions

# Patient Self-Determination Law and Regulation

- *Cruzan v. Missouri Dept. of Health* (1990): US Supreme Court decision establishing constitutional right to refuse treatment
- Federal Patient Self-Determination Act (1990)
  1. right to participate in and direct own health care decisions
  2. right to accept or refuse medical or surgical treatment
  3. right to prepare an advance directive
- New York Public Health Law Art. 29-C
- NY Public Health Law Art. 29-CC, 29-CCC
- NY Public Health Law Art. 29-D
- New York Law, 10 NYCRR Section 405.7

# Legal and Ethical Consensus: Autonomy

- Patients with capacity have a constitutional right to refuse medical treatment, even if that treatment is necessary to sustain life;
- Patients without capacity have the same rights as patients with capacity;
- No right is absolute;
- Decision-making process should generally occur in the clinical setting without recourse to the courts.

# Health Care Proxy

- Everyone needs to complete a health care proxy
- *Health Care Agent* is person appointed to act when patient determined to have lost capacity
- Capacity determinations – task specific, two physicians for decisions to withhold/withdraw life sustaining treatment
- Choosing right health care agent
- Choosing right doctor
- Tell your agent your wishes about tube feeding and IV fluids
- Have early conversations about your wishes and treatment preferences
- Health Care Agent can make decisions about organ donation

# New Legislation

- Family Health Care Decisions Act, effective June 2010
- Palliative Care Information Act, effective February 2011

# Family Health Care Decisions Act

- Establishes the authority of surrogates, family members or friends, to make all health care decisions for patients who have lost decision making capacity, do not have a health care agent and have not left prior instructions regarding care and treatment.

# Family Health Care Decisions Act

- Applicability
  - Applies to decisions for incapable patients in general hospitals and residential health care facilities (nursing homes).
- Does not apply to decisions for patients who
  - have a health care agent
  - have a court appointed guardian under SCPA 1750-A
  - have left prior instructions, pursuant to MOLST or a living will

# Family Health Care Decisions Act

- Priority list to identify surrogate
  - MHL Art. 81 Court appointed guardian
  - Spouse or domestic partner
  - Adult child
  - Parent
  - Sibling
  - Close relative or friend

# Decision Standards

- Requires the surrogate to decide about treatment based on the patient's wishes, including the patient's religious and moral beliefs or, if the patient's wishes are not reasonably known, based on the patient's best interests.
- In assessing the patient's best interests, the surrogate must consider:
  - Dignity and uniqueness of every person
  - Possibility and extent of preserving the patient's life
  - Preservation, improvement or restoration of the patient's health or functioning
  - Relief of the patient's suffering
  - Other values that a reasonable person in the patient's circumstances would wish to consider

# Clinical Criteria and Surrogate Assessment

Authorizes surrogates to make decisions to withhold or withdraw life-sustaining treatment, ***including DNR Orders, if one (or both) of the following conditions apply:***

- Treatment would be an extraordinary burden to the patient **and** the attending physician determines, with concurrence, that patient is terminally ill (expected to die within 6 months) or permanently unconscious; or
- Treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances **and** patient has an irreversible or incurable condition, as determined by attending physician with concurrence (***mandated review in nursing homes by ERC for all decisions other than CPR.***)

# Palliative Ethic of Care

- Palliative ethic of care (Fins, 2006)
- National Consensus Project for Quality Palliative Care defines the goals of palliative care as follows:

*...to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. (National Consensus Project, 2009, p. 6).*

# Central Elements of Palliative Ethic of Care

- Person and family-centered
- Affirms dignity or worth of the person
- Interdisciplinary
- Responds to individual's pain and suffering (Chou et al., 2009; Breitbart et al., 2003)
- Multidimensional understanding of pain and suffering: bodily, cognitive, emotional, spiritual and cultural
- Encourages conversations with loved ones about end-of-life choices, values and treatment preferences
- Empowers individuals to exercise their right to refuse excessively burdensome and invasive medical interventions that provide little or no benefit to the patient and heighten the patient's suffering

# Palliative Care Information Act (PCIA)

The law requires that

- If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient

# Palliative Care Defined

- Palliative Care is defined as health care treatment:
- Including interdisciplinary end-of-life care and consultation with patients and family members,
- To prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice

# PCIA Information and Counseling

It shall include but not be limited to

- The range of options appropriate to the patient
- The prognosis, risks and benefits of the various options
- The patient's legal rights to comprehensive pain and symptom management at the end of life

# PCIA Information Provision

- The information and counseling can be provided by the attending physician or nurse practitioner or by referral or transfer to another appropriate health care practitioner.
- Information can be provided verbally, or in written documents
- Information and counseling would not be provided to a patient who does not want it.

# PCIA Information Provision

Additionally:

- Information and counseling shall be provided to a person with authority to make health care decisions for the patient if the patient lacks decision making capacity.
- Where the attending health care practitioner is not willing to provide the patient with information, counseling arrangements may be made for another physician or nurse practitioner to do so, or the patient shall be referred or transferred to another physician or nurse practitioner willing to do so.

# Palliative Sedation

- Palliative Sedation— Information about palliative sedation to unconsciousness, when other efforts to control symptoms and relieve suffering have been unsuccessful, might also be provided to some dying patients. (See NHPCO, 2010 Statement)

# PCIA Training

Training will be needed.

If the PCIA is to be effectively implemented, a great deal of training will be needed in medical and nursing schools and post-school on palliative and end-of-life care, and physician-nurse practitioner-patient communications.

# MOLST - Goals

## *Designed to:*

- Align medical orders with patient wishes
- Document patient's treatment preferences regarding LST's including CPR, intubation and mechanical ventilation
- Communicate patient wishes regarding care across health care settings
- Improve EMS personnel's ability to provide emergency treatment according to individual's wishes
- Expand palliative care initiatives community-wide
- Reduce repetitive documentation while complying with NYS law and federal law

# Key Elements of MOLST

- Actionable Medical Orders
- Recommended for use with persons who have advanced chronic progressive illness and/or who may wish to further define their end-of-life care wishes
- May be used either to limit medical interventions or to clarify a request for all medically indicated treatments
- Provides explicit direction about resuscitation status if patient  
has no blood pressure, no pulse and no respiration
- Includes directions about other types of interventions that patient may or may not want

# Who Should Have MOLST

- Anyone choosing Do Not Resuscitate
- Anyone who wishes to have a natural death
- Anyone choosing to limit medical interventions
- Anyone who has life-limiting or advanced, chronic progressive illness
- Anyone choosing palliative care at end of life
- Anyone eligible for/residing in LTC facility
- Anyone who might die within next year

# How To Complete MOLST

- Must be completed by health care professionals based on patient wishes, values and treatment preferences
- Must be signed by NYS licensed physician
- Verbal orders given to nurses, nursing supervisors, NP's or PA's are acceptable with follow-up signature by physician in accordance with facility/community policy (within 24 hours in a hospital, 1-7 days in a nursing home)
- Photocopies , faxes and electronic representations of signed MOLST forms are legal and valid
- Complete entire form; sections not completed mean full treatment

# Resources

- Center to Advance Palliative Care  
[capc.org](http://capc.org)
- Collaborative for Palliative Care  
[cpcwestchester.org](http://cpcwestchester.org)
- [Compassionandsupport.org](http://Compassionandsupport.org)
- Compassion & Choices of New York  
[compassionandchoicesofny.org](http://compassionandchoicesofny.org)

# Resources

- Hospice and Palliative Care Association of New York State  
[www.hpcanys.org/members/PCIA/](http://www.hpcanys.org/members/PCIA/)
- New York State Department of Health  
[www.health.ny.gov/professionals/patients/patient\\_rights/palliative\\_care/](http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/)
- Westchester End-of-Life Coalition  
[westchesterendoflife.org](http://westchesterendoflife.org)

# Resources

- Pathways to Care, WJCS – 845 North Broadway, White Plains 10603, 914-761-0600, X 141; Coordinator, Heidi Weiss
- Services: care management, emotional support, advocacy, spiritual care coordinator, holistic nurse for persons with chronic disease and terminal diagnoses

# Resource Information

Pathways for Care, WJCS

Collaboration for Physician Consultative  
Service

Unmet needs: pain management, sleep  
issues,  
medication management.

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# Death Is Not the Worst Thing

“A recent survey stated that the average person’s greatest fear is having to give a speech in public. Somehow this ranked even higher than death, which was third on the list. So, you’re telling me that at a funeral, most people would rather be the guy in the coffin than have to stand up and give a eulogy.”

*Jerry Seinfeld*

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