ECHO MOLST + eMOLST: *Honoring Preferences at End-of-life*

Session 4 Ethics and the Law: Updates on PHL, Authority and Accountability

Presenter

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The speaker has no significant financial conflicts of interest to disclose.

Learning Objectives

- Define the ethical framework for making end-of-life decisions
- Recognize the ethical framework is the basis for legal requirements in NYS Public Health Law (PHL)
- Explain the clinical standards under PHL
- Describe the impact of recent changes in PHL

Ethical Standards

Hierarchy of Medical Decision-Making

- Patient's Current Wishes
  - If the patient has decisional capacity, this **ALWAYS** takes precedence.
- Substituted judgment
  - Done by the surrogate decision-maker - only when the patient is not fully capable of making decisions
  - Based on the patient's prior values and wishes
  - Making decisions as the patient would
  - Advance directive is used as a *guide*
  - Patient input, when possible, even if patient is not fully capable of making the decision
  - Health care agent or surrogate (FHCDA or §SCPA 1750-b)

Hierarchy of Medical Decision-Making

- Best interest
  - Done by the health care agent or surrogate (FHCDA or §SCPA 1750-b) when the patient lacks decisional capacity and evidence does not exist for substituted judgment
  - Balancing benefits and burdens
  - Input from caregivers is important, but must focus on the patient's – not the caregiver's best interest
  - Using values and beliefs, when there is no surrogate, and no knowledge of patient values, beliefs, goals or prior wishes with respect to end-of-life care

Challenges:
Patient *with* Capacity

- Choose right Health Care Agent (HCA) and complete a health care proxy (HCP)
- If no HCP exists & patient has capacity, do HCP
- Encourage patient's family to do the same
- Develop goals for care with the patient
- Discuss patient goals for care with family and loved ones
- Clarify medical decisions are patient-centered and remain so if the patient loses capacity (substituted judgment)

Challenges:
Patients *without* Capacity

- Empower the designated HCA
- If no HCP and patient retains decisional capacity to choose a HCA, complete a HCP
- HCA uses substituted judgment
- *Always* engage families in the process
- *Always* consider the patient's goals
- Provide both choice and guidance
- Consider quality of life and personhood for patients who cannot speak for themselves

Practical Strategies:
Clarifying Best Interest When Patients Lack Capacity

Meet	Meet with the patient, health care agent/surrogate, family and key caregivers
Allow	Allow each person to tell their story
Integrate	Integrate capacity determination
Be	Be honest and direct about the diagnosis
Respond	Respond to emotions elicited
Identify	Identify areas of agreement and disagreement

Practical Strategies:
Clarifying Best Interest When Patients Lack Capacity

- Best Interest
  - To be respected and understood as people
  - To have their goals and values honored including personhood, spirituality, dignity
  - To lessen suffering and enhance quality of life
- Useful guide for physicians, NPs, PAs when the patient lacks capacity and does not have a health care agent or surrogate

Legal Requirements Vary

Based on the person who makes the decision and where the decision is made

8-Step MOLST Protocol

Developed for NYS MOLST, Bomba, 2005; revised 2011

1. Prepare for discussion
   - Understand patient's health status, prognosis & ability to consent
   - Retrieve completed Advance Directives
   - Determine decision-maker & PHL legal requirements
2. Determine what the patient/family know
3. Explore goals, hopes and expectations
4. Suggest realistic goals
5. Respond empathetically
6. Use MOLST to guide choices & finalize patient wishes
   - Shared, informed medical decision-making and conflict resolution
7. Complete and sign MOLST
   - Follow PHL and document conversation
8. Review and revise periodically

Health Care Proxy Law

MOLST Instructions and Checklists Ethical Framework/Legal Requirements

Checklist #1 - Adult patients with medical decision-making capacity *(any setting)*

Checklist #2 - Adult patients without medical decision-making capacity who have a health care proxy *(any setting)*

Checklist #3 - Adult hospital or nursing home patients without medical decision-making capacity who do not have a health care proxy, and decision-maker is a Public Health Law Surrogate (surrogate selected from the surrogate list); includes hospice

Checklist #4 - Adult hospital or nursing home patients without medical decision-making capacity who do not have a health care proxy or a Public Health Law Surrogate (*+/- hospice eligible)*

Checklist #5 - Adult patients without medical decision-making capacity who do not have a health care proxy, and the MOLST form is being completed in the *community*.

Checklist for Minor Patients - (*any setting)*

Checklist for Developmentally Disabled who lack capacity – *(any setting)* **must** travel with the patient's MOLST

http://www.nyhealth.gov/professionals/patients/patient_rights/molst/

Health Care Proxy Law

- Capacity determination
- Health care agents are *required to make decisions according to the patient's wishes*, including the patient's religious and moral beliefs.
- If the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, the health care agent may make decisions according to the *patient's best interests*, except a decision to withhold or withdraw artificial nutrition or hydration.
- Health care agents are authorized to make a decision to withhold or withdraw artificial nutrition or hydration only if they know the patient's wishes regarding the administration of artificial nutrition and hydration
- *Notification* if patient resides in a correctional facility

Family Health Care Decisions Act
Article 29-CC

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Family Health Care Decisions Act (FHCDA)

- Part of Laws of 2010, Chapter 8, effective June 1, 2010
- FHCDA is Public Health Law (PHL) Article 29-CC.
- PHL Article 29-CC is applicable in general hospitals and residential health care facilities (nursing homes).
- Laws of 2010, Chapter 8 also repealed PHL § 2977 (Nonhospital orders not to resuscitate) and created a new PHL Article 29-CCC (Nonhospital Orders Not to Resuscitate). MOLST is the only alternate form approved by the Commissioner of Health, under 29-CCC, per successful legislated community pilot (2005-2008).

Jonathan Karmel, Esq., NYSDOH, EMS Briefing, May 2010

Clinical Standards for DNR Order Changed with FHCDA

- No “therapeutic exception”
- Clinical standards
  - patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided
  - patient is permanently unconscious
  - 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 an irreversible or incurable condition
- CPR would be medically futile is **not** a clinical standard (vs. Article 29-B)

FHCDA Clinical Standards: When an Incapacitated Patient Has A Surrogate

1. Treatment would pose an extraordinary burden to the patient, as determined by attending physician, NP* or PA** *and* independent concurrence of another physician, NP* or PA** and:
   - Patient has an illness or injury which can be expected to result in death in less than 6 months whether or not treatment is provided, **or**
   - Patient is permanently unconscious
2. Clinical condition is irreversible or incurable, and provision of treatment would involve such pain and suffering that it is deemed inhumane or extraordinarily burdensome

Jonathan Karmel, Esq., NYSDOH, EMS Briefing, May 2010
*FHCDA amended, effective May 28, 2018
**FHCDA amended, effective June 17, 2020

FHCDA Special Requirements
Ethics Committee or Court Determination

Hospital	If attending physician, NP or PA objects to WH/WD declining AHN
Nursing Homes	MOLST orders other than a DNR order
Ethics Review Committee	Includes at least one physician, NP or PA who is not directly responsible for patient's care Determines the orders meet the patient-centered and clinical standards

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Clinical Standards & Special Considerations (Nursing Home)
No HCA & No FHCDA Surrogate is Identified (*DOH MOLST Checklist 4*)

- Patient may be enrolled in hospice with a plan of care that includes MOLST, if two physicians, NPs**, or PAs*** & Ethic Review Committee agree that patient meets certain criteria*
  - same criteria that would apply to a decision by a surrogate under Checklist 3
  - includes consultation with staff directly responsible for patient's care
  - physicians, NPs**, PAs*** serve as surrogates & make decisions on behalf of the incapacitated patient
  - applies if patient is already in hospice
- If the patient is not enrolled in Hospice, life-sustaining treatment may be withheld from a patient in nursing home without a HCP or a surrogate, only if
  - a court makes the decision or
  - two physicians, NPs**, or PAs*** authorized by the facility concur that the patient would die imminently, even if the patient received the treatment, & provision of the treatment would violate accepted medical standards

*2015 Amendment to FHCDA; **2018 Amendment to FHCDA; ***2020 Amendment to FHCDA

HCP and FHCDA Law

MOLST Decisions by HCA & FHCDA Surrogates

- required to make decisions according to patient's *known wishes*, including patient's religious & moral beliefs or *best interest* **NOT** HCA or Surrogate

Shared Decision-Making and Informed Consent

- resident's medical condition
- risks, benefits, burdens and alternatives of possible LST

- Health Care Agents
  - generally authorized to make decisions as if they were the patient
- FHCDA Surrogates
  - must meet clinical standards and special considerations

Decisions by Adults with Capacity under FHCDA

- Even if the patient lacks capacity, there is **no** surrogate decision-making where the patient has already made a decision about the health care prior to losing capacity:
  - in writing or orally
  - with respect to a decision to withdraw or withhold life-sustaining treatment, such oral consent must be during hospitalization in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital

Jonathan Karmel, Esq., NYSDOH, EMS Briefing, May 2010

Decisions by Adults with Capacity under FHCDA

MOLST represents "clear and convincing" evidence of patient preferences

- Requires proper completion of the MOLST process
  - 8-Step MOLST Protocol
  - Appropriate Checklist (ethical-legal requirements)
- Resuscitation: Life-Sustaining Treatment under FHCDA
- Completion of MOLST as a "form with check boxes" or "interpretation of a living will" without a discussion(s) is wrong and results in conflict.

Use language that respects the patient's decision

- Do NOT ask decision-maker to decide. *The patient has already made the decision*.
- "Your loved one made a decision to not attempt resuscitation based on understanding their health status, prognosis at the time the decision was made. We must respect their decision. It is a gift of love that they made the decision themselves. Their medical condition is much worse now. We must focus on other decisions today."

What a Health Care Agent or FHCDA Surrogate Can *and* Cannot Do

- Cannot Do
  - If the patient loses the ability to make MOLST decisions and the patient has already made decisions to withhold certain life-sustaining treatment (e.g., Do Not Resuscitate (DNR) and Do Not Intubate (DNI), the health care agent or surrogate cannot undo the patient's decision.
- Can Do
  - If the patient loses the ability to make MOLST decisions and the patient has requested full treatment for certain life-sustaining treatment, the health care agent or surrogate can make a decision to withhold and/or withdraw other life-sustaining treatment on the MOLST for which the patient requested full treatment, as full treatment represents the standard of care.

Bomba PA, Karmel J. Medical, Ethical and Legal Obligations to Honor Patient Preferences. NYSBA Health Law Journal Spring/Summer 2015; 20(2):28-33

Family Health Care Decisions Act
Article 29-CCC
"Clear & Convincing Evidence"

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MOLST Use in Community: Patient Lacks Capacity & no HCP NYSDOH and Change in NYSPHL

- **2005**: DOH approves MOLST use in all NY hospitals and nursing homes. A Non-hospital DNR form to accompany MOLST at care transitions
- **2005-2008**: DOH supported a legislated community pilot to assess EMS ability to follow DNR and DNI on an *alternate form*, i.e., MOLST
- **July 7, 2008**: NYSPHL amended due to successful community pilot (2005-2008)
  - MOLST approved as an alternate form by the late Commissioner of Health, Dr. Richard Daines
  - Result: EMS can honor DNR and DNI orders on MOLST forms statewide
  - ALL health care professionals MUST follow MOLST in ALL settings
- **June 1, 2010**: FHCDA goes into effect
  - New PHL Article 29-CCC (Nonhospital Orders Not to Resuscitate)
  - MOLST is the only alternate form approved by the Commissioner of Health, under 29-CCC, per successful legislated community pilot (2005-2008). No other form tested.
  - FHCDA Surrogate can work with physician, NP*, PA** to complete Resuscitation Preference and Respiratory Support (make DNR/DNI decisions)
  - Physician, NP*, PA** uses “clear and convincing evidence” to complete the rest of the MOLST
  - “Clear & convincing evidence”: living will or repeated oral expression

FHCDA, effective June 1, 2010
*FHCDA amended, effective May 28, 2018
**FHCDA amended, effective June 17, 2020

Notifications

Resident in Mental Hygiene Facility

- MHLS
- Director of the facility
- Checklist 3, 4

Resident in Correctional Facility

- Director of the facility
- Checklist 1, 2, 3, 4, 5

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Surrogate Court Procedures Act §1750-b

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SCPA §1750-b Process

Step 1	Identification of 1750-b Surrogate from Prioritized List
Step 2	1750-b Surrogate and Physician have conversation(s). Surrogate requests WH/WD LST
Step 3	Confirm Capacity; follow the requirements
Step 4	Determine Necessary Medial Criteria
Step 5	Notifications: In or transferred from OPWDD facility: Facility Director and MHLS; Not in OPWDD facility: Director of DDSO
Step 6	Certify the 1750-b process is complete and there are no objections BEFORE signing the MOLST

SCPA §1750-b Clinical Standards

- An individual with I/DD who lacks capacity has
  - A terminal condition, **OR**
  - Permanent unconsciousness, **OR**
  - A medical condition other than DD which requires LST, is irreversible & will continue indefinitely

AND

- The LST would impose an extraordinary burden on the individual in light of:
  - The person's medical condition other than the DD **AND**
  - The expected outcome of the LST, notwithstanding the person's DD

- For WD/WH artificial hydration/nutrition
  - There is no reasonable hope of maintaining life **OR**
  - The AHN poses an extraordinary burden

Decision-maker	Can NP Sign the MOLST? (subject to the usual constraints on an NP)	Explanation
Decision by Patient (directly or by advance directive)	Yes	Falls within NP's scope of practice. No statutory limitation. NP can write the order.
Decision by health care agent	Yes, amended February 3, 2019	The health care proxy law requires the "health care provider" to honor decisions by agent. "Health care provider" would include a NP. NP can write the order.
Decision by FHCDA surrogate	Yes, as of May 28, 2018	Currently, the FHCDA specifies that the attending physician must implement the surrogate's decision. PHL 2994-F. The definition of attending physician (effective May 28) will include nurse practitioner. So, as of May 28, 2018, an NP can write the order.
Decision by an § SCPA 1750-b surrogate (decisions for patients with intellectual disabilities)	No	SCPA 1750-b.4(d) provides that it is the "attending physician" who must write the order.

Adapted from tables created by Robert N. Swidler, V.P. Legal Services, St. Peter's Health Partners, Albany NY

Decision-Maker	Can PA Sign the MOLST?	Explanation
Patient	Yes, as of June 17, 2020	Falls under PA's scope of practice. No limitation. PA can write the order.
Health Care Agent	Yes, as of June 17, 2020	The Health Care Proxy Law requires the "health care provider" to honor decisions by the agent. "Health care provider" would include a PA. PA can write the order.
FHCDA surrogate	Yes, as of June 17, 2020	Updates to the FHCDA in 2019 specified that the "attending practitioner" must implement the FHCDA Surrogate's decision. The "attending practitioner" includes a physician. nurse practitioner or physician assistant. As of June 17, 2020, the PA can write the order.
§ SCPA 1750-b surrogate (decisions for patients with intellectual/developmental disabilities who lack capacity to make medical decisions and lack capacity to complete a health care proxy)	No	§ SCPA 1750-b requires that it is the "attending physician" who must write the order. The 2019 PA bill did not change this.

Adapted from tables created by Robert N. Swidler, V.P. Legal Services, St. Peter's Health Partners, Albany NY

Key Points

Health Care Proxy Law, Family Health Care Decisions Act (FHCDA) that incorporates MOLST as only approved alternate form to Non-hospital DNR form in community, and SCPA §1740-b govern EOL medical decisions in NYS.

Ethical principles and NYSPHL affirm end-of-life decisions to withhold &/or withdraw MUST be consistent with the patient's personal values, beliefs and goals for care –With or Without MOLST.

MOLST represents "clear and convincing" evidence of patient preferences.

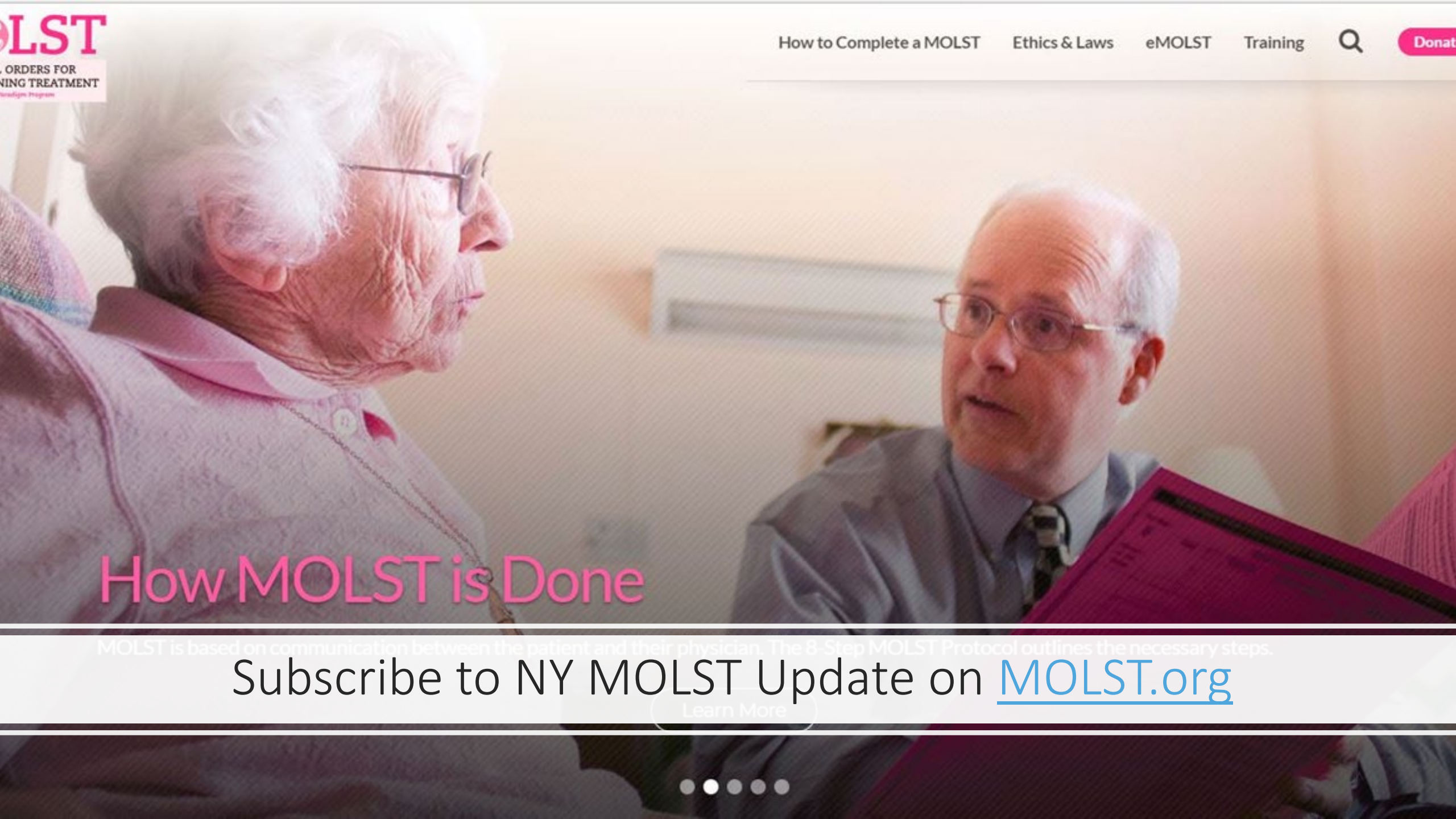
Authority of NPs & PAs is expanded under PHL. NPs and PAs have authority & accountability for MOLST and can sign MOLST.

For hospice eligible incapacitated patients with no HCP or FHCDA Surrogate, the physician, NP or PA can provide hospice services and complete a MOLST with clinical standards & requirements that align with Checklist #3.

For non-hospice eligible incapacitated patients with no HCP or FHCDA Surrogate, clinical standards remain "imminently dying". Thus, continued screening for hospice and MOLST appropriateness is warranted.

PHL Article 29-CCC (Nonhospital Orders Not to Resuscitate) permits FHCDA Surrogate to make DNR/DNI decisions on MOLST in the community; "clear & convincing evidence guides other medical orders.

Resources



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- MOLST.org
  - Ethics & Law
  - Ethical and Legal Requirements
  - Authority of a Health Care Agent & Surrogate
  - Authority of Nurse Practitioners & Current NYS Law
  - Authority of Physician Assistants as of June 17, 2020