ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)
Session 6
Shared Decision Making and MOLST

Presenters

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The speakers have no significant financial conflicts of interest to disclose.
Learning Objectives

• Describe and apply the 8-Step MOLST Protocol
• Define shared decision-making process for medical orders
• Identify requirements of guardian/surrogate decision maker
• Explain the determination and proper documentation of necessary medical criteria for decisions to withhold/withdrawal life-sustaining treatments
8-Step MOLST Protocol
Patients Have Right to Make EOL Decisions

Value of MOLST/eMOLST vs. Nonhospital DNR Form vs. Facility Forms

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of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked.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.

DOH-3474 (2/92)

MOLST Requires a Thoughtful Discussion or a Series of Discussions
Communication Challenges

Limited evidence base on end-of-life needs in adult I/DD population, especially those in community residence

Communication barriers

- Impact Symptom Assessment & Management
- Can lead to diagnosis of illness at more advanced stage
- Less involvement of patient in decision making

Patient’s lack of comprehension of their illness, symptoms, or treatments

- May interpret illness or treatments as punishment for wrongdoing.
- May not be able to understand death and why their family/caregivers are sad around them.

Ellison & Rosielle. Palliative Care Network of Wisconsin. Fast Facts # 192
Questions to Help a Patient, Health Care Agent or 1750-b Guardian Prepare for a MOLST Discussion

• What do you understand about your current health condition?
• What do you expect for the future?
• What makes life worth living?
• What is important to you?
• What matters most to you?
• How do you define quality of life?
• Would you trade quality of life for more time?
• Would you trade time for quality of life?
8-Step MOLST Protocol

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, SCPA §1750-b and document conversation
   - If person with IDD lacks capacity & no HCA, physician signs MOLST After OPWDD Checklist is completed and No objection is raised

8. Review and revise periodically

Developed for NYS MOLST, Bomba, 2005; revised 2011

- Developed Based on My Clinical Practice since 1979
- Prior to NY MOLST
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/
Estimate and Communicate Prognosis

- Physicians markedly over-estimate prognosis
- Accurate information helps patient/family cope & plan
- Offer a range for average life expectancy
  - days to weeks
  - weeks to 3 months
  - 3 – 6 months (PCIA, PCAA, Hospice*)
  - 6 months to 1-2 years (MOLST**)
  - > 1year (MOLST: e.g. persons of advanced age may have explicit wishes.)

* Would it surprise you if this person died in the next 6 months?
** Would it surprise you if this person died in the next 1-2 years?
Care Plan

• Palliation
  • Pain and symptom management
• Who Will Assess in an Emergency
• Supportive care
  • Patient
  • Family
  • Staff
Shared Decision-Making
Shared, Informed Medical Decision Making

- Will treatment make a difference?
- What are the burdens and benefits?
- Is there hope of recovery?
- What does the patient value?

- Will treatment help or harm the patient?
- If so, what will life be like afterward?
- What are the patient’s goals for care?
Resuscitation Preferences
Cardiac Arrest

- Define CPR
- Success rate of CPR
  - Advanced illness ≤ 2.0%
  - Moderate frailty-terminal illness: <2%
- Reality of COVID-19
- DNR: Do Not Attempt Resuscitation (Allow Natural Death)
- DNR and DNI are distinct medical orders
- DNR does **NOT** mean Do Not Treat
Respiratory Support
Cardiac or Pulmonary Insufficiency

- Survival rates depend on:
  - Factors present at start of ventilator support
  - Development of complications
  - Patient management in ICU
  - Patients with advanced illness/frailty: high risk
- 2012 Study 1019 patients: Six-month mortality rates*
  - 51% in very old patients
  - 67% for DNI patients
  - 77% in case of NIV failure and endotracheal intubation
- Trial period
  - determine if there is benefit based on the patient’s current goals for care

Defining a Trial Period

- A trial of life-sustaining treatment may be ordered if the physician or NP or PA agrees it is medically appropriate.
- A trial is used to determine if there is benefit to the patient. A trial is based on the patient’s current goals for care.
- If a life-sustaining treatment is started but turns out not to be helpful and does not meet the patient’s goals for care, treatment can be stopped.
- Additional procedures may be needed for patients with developmental disabilities (see page 4).
Hospitalization/Transfer Preferences

- A patient who does not wish to go back to the hospital needs
  - Palliative care plan
  - 24/7 plan for assessment if an emergency arises
  - 24/7 plan for management of pain and symptoms
  - Provision of basic care needs in the current setting
  - Caregiver education, support and respite

- **Assessment** is required if an acute issue arises, and the patient does not wish to be hospitalized
Conflict Resolution

• Manage conflict within the family, within the team and between the patient/family and team with skill and empathy

• Apply the approach to a crucial conversation to resolve conflict
Requirements for a §SCPA 1750-b Surrogate
Ethical Hierarchy of Medical Decision-Making

Patient’s Current Wishes

• If the patient has decisional capacity, this **ALWAYS** takes precedence.

Substituted judgment

• Done by the Health Care Agent or §SCPA 1750-b surrogate - only when the patient is not fully capable of making decisions
• Based on the patient’s prior values & 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
Ethical Hierarchy of Medical Decision-Making

• Best interest
  • Done by the Health Care Agent or §SCPA 1750-b surrogate 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
Responsibility of Surrogates

Advocate for efficacious treatment.

Base decisions on best interests, and when known, the person’s wishes including moral and religious beliefs.

Statutory best interest considerations include - dignity and uniqueness of the person, preserve, improve or restore health; relief from suffering.

SCPA 1750-b (2) & (4)
Necessary Medical Criteria to WH/WD LST
Life Sustaining Treatment (LST)

Medical treatment which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period.

Includes CPR, mechanical ventilation, hemodialysis, and artificial nutrition and hydration.

SCPA 1750-b(1)
Role of Physician - Medical Criteria

Attending/concurring physician determine to a reasonable degree of certainty

1. patient has a terminal condition; OR
2. is permanently unconscious; OR
3. has a medical condition other (other than a developmental disability) that is irreversible and will continue indefinitely; (COPD, CHF, dementia)
4. AND, the proposed treatment would impose an extraordinary burden to the individual.

SCPA 1750-b(4)(b)
Extraordinary Burden Considerations

1. the person’s medical condition other than the person’s developmental disability
2. the expected outcome of the LST, notwithstanding the person’s developmental disability

SCPA 1750-b(4)(b)
Role of Physician - Artificial Hydration and Nutrition

Additional requirement of finding that ANH itself poses an extraordinary burden to the person

OR

There is no reasonable hope of maintaining life

SCPA 1750-b(4)(b)
Key Points

- MOLST requires thoughtful discussion that ensures well-informed shared decision-making.
- The 8-Step MOLST Protocol is integrated with the OPWDD Checklist to ensure proper completion of MOLST.
- The attending and concurring physician are responsible for determining medical criteria.
- The attending and concurring physician are responsible for determining extraordinary burden.
- MOLST is not merely a form to be completed.
- Additional requirements exist for feeding tubes and will be addressed in a separate session.
Resources
Redesigned CompassionAndSupport.org

A project of the Community-wide End-of-life/Palliative Care Initiative
How MOLST is Done

MOLST is based on communication between the patient and their doctor. The 8-step MOLST Protocol outlines the necessary steps.

Subscribe to NY MOLST Update on MOLST.org
Web Resources

- Thoughtful MOLST Discussions: [8-Step MOLST Protocol](#)
- [MOLST Form](#) and individual web pages
  - Resuscitation Preferences
  - Respiratory Support
  - Future Hospitalization/Transfer
  - Feeding Tubes
  - Antibiotics
  - Dialysis
  - Other Instructions
  - Review and Renew
Videos

Demonstrating Thoughtful MOLST Discussions
- Hospital & Hospice Settings
- Nursing Home Setting

Patient & Family Education
- Writing Your Final Chapter: Know Your Choices. Share Your Wishes - Original release 2007; revised to comply with FHCDA - MOLST Video Revised 2015! (28:14)
  https://youtu.be/CITAG19RX8w

CompassionAndSupportYouTubeChannel (ACP/MOLST video playlists)
http://www.youtube.com/user/CompassionAndSupport?feature=mhee

New CPT Codes for ACP & MOLST Discussions (02/02/16 Webinar Recording)
https://youtu.be/VCV26ZyGgwY
References

- Health Care Decisions OPWDD webpage: https://opwdd.ny.gov/providers/health-care-decisions


- More at Resources on MOLST.org
References

• Books Beyond Words  https://booksbeyondwords.co.uk/
• Disability Distress and Assessment Tool (DisDAT)  
• Vital Talk - evidence based communication techniques for clinicians  www.vitaltalk.org/