ECHO MOLST + eMOLST: Honoring Preferences at End-of-life
Session 2
More Than a Form – It’s a Process

Presenter

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Founder, MOLST and eMOLST Programs
Founder & Emeritus Chair, MOLST Statewide Implementation Team
Co-Founder, National POLST

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

• Explain the differences between MOLST, the Non-hospital DNR form and facility forms

• Describe the 8-Step MOLST Protocol, a standardized process designed to improve quality and prevent medical errors

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of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked.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

Completion of MOLST is **Voluntary**

**Screen and Offer** MOLST to All Appropriate Patients

1. Patients whose physician, NP or PA would not be surprised if they die in the next 1-2 years

2. Patients who live in a nursing home or receive long-term care services at home or in an adult care facility (e.g. assisted living)

3. Patients who want to avoid and/or receive any or all life-sustaining treatment today

4. Patients who have one or more advanced chronic conditions or a new diagnosis with a poor prognosis

5. Patients who have had two or more unplanned hospital admissions in the last 12 months, coupled with increasing frailty, decreasing functionality, progressive weight loss or lack of social support
MOLST Requires Thoughtful Discussion or a Series of Discussions
Questions to Help a Patient 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?
Patient Education: Websites & Videos

Practice Site Workflow and Accountability

Websites: MOLST.org and CompassionAndSupport.org

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/CIrAG19RX8w
Community Partners in Advance Care Planning
https://youtu.be/JKEMouEgGh8

Demonstrating Thoughtful MOLST Discussions

Hospital & Hospice Settings
Nursing Home Setting

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

8. Review and revise periodically

Developed for NYS MOLST, Bomba, 2005; revised 2011
Clinical Frailty Scale

1. **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. **Well** – People who have no active disease symptoms but are less fit than Category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. **Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. **Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up,” and/or being tired during the day.

5. **Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. **Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need

7. **Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy < 6 months, who are not otherwise evidently frail.

Where dementia is present, the degree of frailty usually corresponds to the degree of dementia:

- **Mild dementia** – includes forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

- **Moderate dementia** – recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

- **Severe dementia** – they cannot do personal care without help.

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Estimate and Communicate Prognosis

- Physicians markedly over-estimate prognosis
- Accurate information helps patient / family cope and 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?
Who Makes the Decision?

- Patient
- Health Care Agent
- FHCDA Surrogate
- No FHCDA Surrogate
- SCPA 1750-b Surrogate
Capacity Determination: Who Makes Decision

DOH and OPWDD MOLST Checklists: Ethical legal requirements vary, based on Who Makes the Decision & Where It Is Made

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

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8. Review and revise periodically
**Determine What the Patient & Family Know re: Health Status & Prognosis**

**Begin**
Begin with an open-ended question. Be present. Actively listen.

*What have you heard from other doctors about your condition?*

**Inform**
Inform the patient they are appropriate for a MOLST discussion based on MOLST screening questions.

**Offer**
Offer the opportunity to continue. Patients may not ready to accept their condition and prognosis. If so, return to discussion at a future date.

**Respond**
Respond with emotion and empathy.
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Developed for NYS MOLST, Bomba, 2005; revised 2011
Identify patient’s personal values and beliefs

- What makes life worth living
- What matters most

Recognize patient’s personal goals for care

- Longevity
- Functional Preservation
- Comfort Care

Patient’s personal goals align with

Are goals realistic?

Does COVID-19 or other emergency change this?
8-Step MOLST Protocol

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Developed for NYS MOLST, Bomba, 2005; revised 2011
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?
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
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Developed for NYS MOLST, Bomba, 2005; revised 2011
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
Treatment Guidelines

No matter what is chosen, **ALL** patients receive **comfort measures**.

- Comfort measures only
- Limited medical interventions
- No limitations on medical interventions
Artificially Administered Fluids & Nutrition

Food and fluids are always offered as tolerated

Feeding Tubes
- No feeding tube
- A trail of feeding tube
- Long-term feeding tube, if needed

IV Fluids
- No IV fluids
- A trial of IV fluids
# Long Term Feeding Tube Guidelines

## Benefits/Burdens of Tube Feeding/PEG Placement for Adults

<table>
<thead>
<tr>
<th>Benefits of PEG placement rather than feeding orally:</th>
<th>Burdens of feeding orally rather than inserting a PEG</th>
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<tbody>
<tr>
<td>For dysphagia stroke patients in previous good health, patients with ALS, and patients in a persistent vegetative state, may prolong life.</td>
<td>Patient able to enjoy the taste of food</td>
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<tr>
<td>For dysphagia stroke patients in previous poor health, may prolong life in the short term (days to weeks).</td>
<td>Patient has greater opportunity for social interaction</td>
</tr>
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<td>Enables family members/caregivers to maintain hope for future improvement.</td>
<td>Patient’s wishes and circumstances can be taken into consideration as pertinent to pain, living, and volume of feeding</td>
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<td>Enables family members/caregivers to avoid guilt/conflict associate with choosing other treatment options.</td>
<td>Patient/family worry about “not doing everything in their power” to address the feeding problem and “frustrating patient”</td>
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<td>Allows family members/caregivers additional time to adjust to possibility of impending death.</td>
<td>Patient/family feel that it is not enough time that could possibly prolong life, they are hastening death</td>
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## Advantages of Prolonging Life

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## Improved Quality of Life and/or Functional Status

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## Enables Potentially Curative Therapy/Reverses the Disease Process

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This grid reflects only certain conditions. Some examples of other conditions where enteral feeding would be indicated include: radical neck dissections, esophageal cancers and motility diseases, post-infectious esophageal surgery and other conditions when the alternative would be parenteral hyperalimentation.
Antibiotics

• Do not use antibiotics
• Determine use or limitations of antibiotics when infection occurs
• Use Antibiotics to treat infections
Other Medical Orders and Instructions

Examples
- Dialysis
- Implantable Defibrillators
- Transfusions

Goals for a Trial
- Live longer
- Preserve Functional Status
- Comfort
Care Plan

• Palliation
  • Pain and symptom management

• Who Will Assess in an Emergency

• Supportive care
  • Patient
  • Family
  • Staff
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Review and Renew MOLST

• The physician or NP or PA must review, sign & date the MOLST at least every 90 days, (and in accordance with policies & procedures)

• The physician or NP or PA must also review, sign & date the MOLST form if any of these apply:
  • If the patient moves from one location to another to receive care
  • If the patient has a major change in health status (for better or worse)
  • If the patient or decision-maker (*Health Care Agent, FHxDA or §1750-b Surrogate, Parent or Guardian*) changes their mind about a treatment decision they made
NYSDOH Releasing a Revised MOLST Form in 2022

• Revision
  • follows the multi-year NYSDOH RFI process
  • opportunities for improvement & clarification from relevant stakeholders, including patients & families

• Clinical edits
  • gathered from its heavy use during COVID-19
  • Feedback from physicians, NPs, PAs, EMS, and other clinicians who use MOLST/eMOLST every day

• At a high level, the RFI process revealed
  • many clinicians experience the current MOLST as complex and wordy
  • emergent orders could be captured more simply
  • clarification needed in the respiratory support section
  • patients want to have a clearer “do not hospitalize” option

• Exact launch date is uncertain
  • NYSDOH working collaboratively with the MOLST Statewide Implementation Team and eMOLST to ensure a careful transition takes place
  • Communication and education to be available to clinicians, administrative leaders, patients, & families

• For updates as they become available, please visit the NYSDOH MOLST web page & MOLST.org
MOLST requires thoughtful discussion that ensures well-informed shared decision-making.

Physicians, NPs (as of 2018 for FHCDA & 2019 for HCP law) and PAs (as of 6/17/2020) have authority and are accountable for accurate completion of MOLST.

Only a physician, not an NP or PA, has authority, is accountable and can sign the MOLST for Persons with DD/ID who lack capacity after completing the OPWDD Checklist.

MOLST is NOT completed by checking off boxes on a form.

MOLST needs to be reviewed and reviewed as MOLST is a set of medical orders.
How MOLST is Done

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

Subscribe to NY MOLST Update on MOLST.org
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
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
References


• More at Resources on MOLST.org