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 & Emeritus Chair, MOLST Statewide Implementation Team

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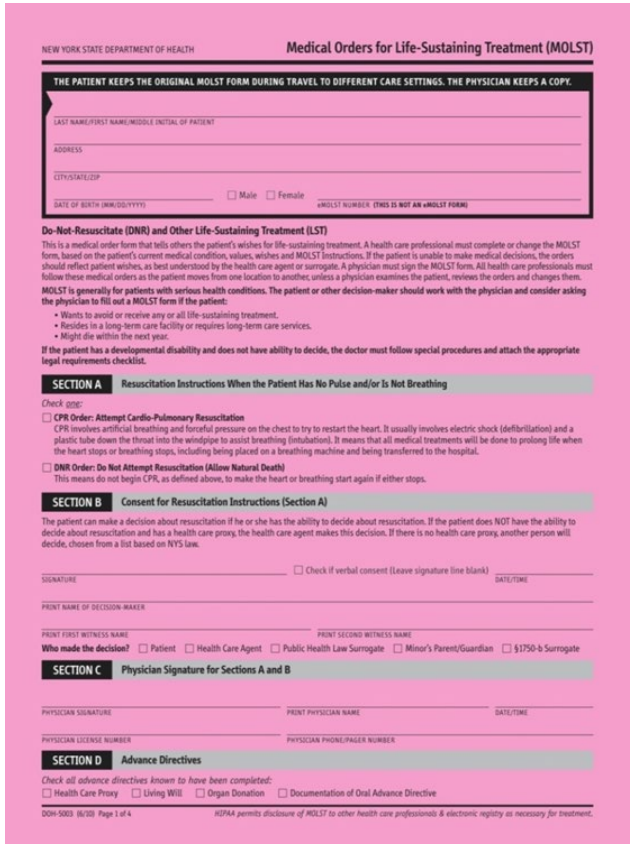
The speaker has no significant financial conflicts of interest to disclose.

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



NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing

Check one:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

SECTION B Consent for Resuscitation Instructions (Section A)

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION-MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decision? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate

SECTION C Physician Signature for Sections A and B

PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

PHYSICIAN LICENSE NUMBER PHYSICIAN PHONE/PAGER NUMBER

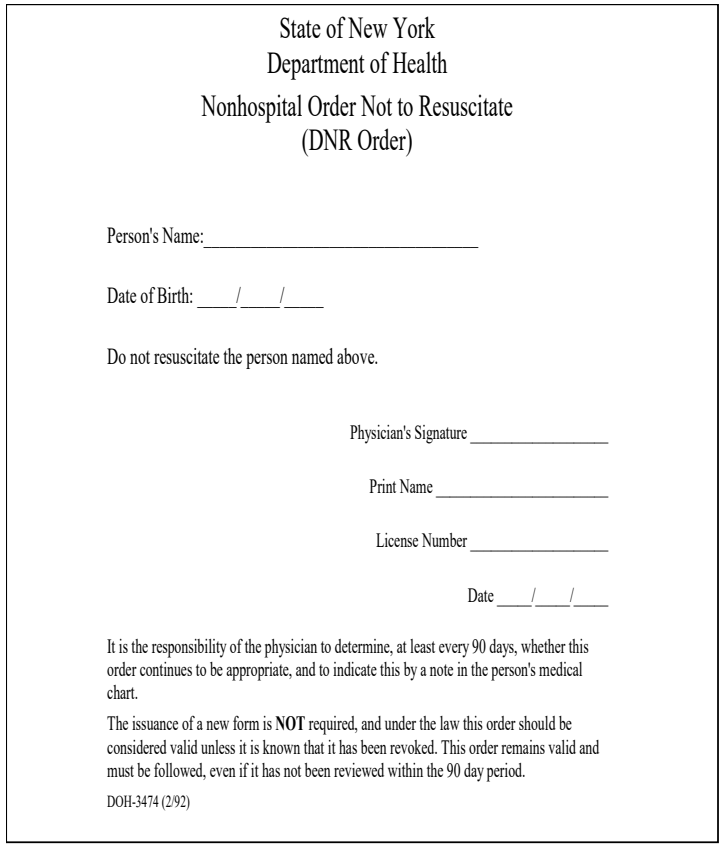
SECTION D Advance Directives

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

DOH-5003 (6/10) Page 1 of 4 *HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment.*

https://www.health.ny.gov/forms/doh-5003.pdf



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?

MOLST
MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT
A POLST Paradigm Program

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/ClTAG19RX8w

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

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

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.

Assess Health Status:

Clinical Frailty Scale

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 1-2years?

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

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

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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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Patient Values, Beliefs, Goals for Care, Expectations

Identify patient's personal values and beliefs

Recognize patient's personal goals for care

- What makes life worth living
- What matters most

Patient's personal goals align with

- Longevity
- Functional Preservation
- Comfort Care

Are goals realistic?

Does COVID-19 or other emergency change this?

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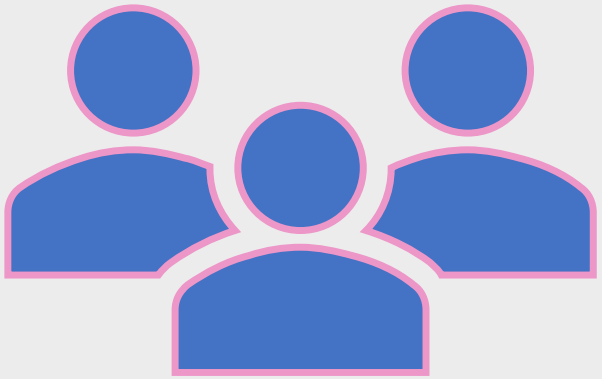
Shared, Informed Medical Decision Making

Will treatment make a difference?	
What are the burdens and benefits?	• Will treatment help or harm the patient?
Is there hope of recovery?	• If so, what will life be like afterward?
What does the patient value?	• 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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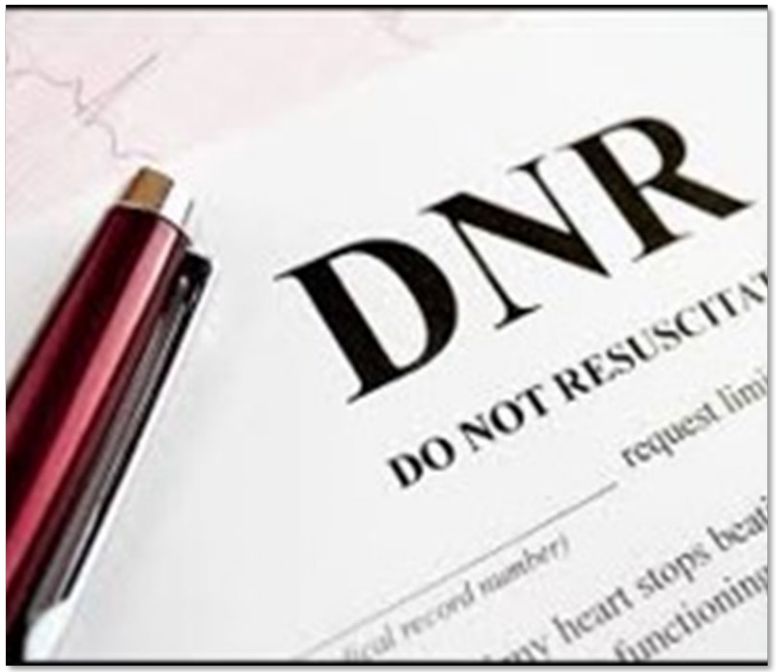
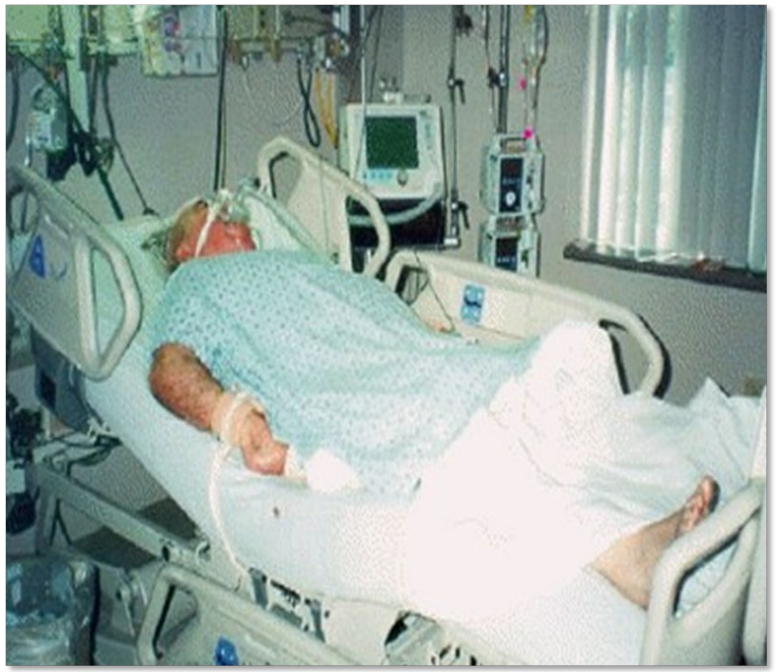
Resuscitation Preferences
Cardiac Arrest



- 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



*Schortgen, F., Follin, A., Piccari, L., Roche-Campo, F., Carteaux, G., Taillandier-Heriche, E., . . . Brochard, L. (2012). Results of Noninvasive Ventilation in Very Old Patients. Annals of Intensive Care, 2(5). doi:10.1186/2110-5820-2-5

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

Monroe County Medical Society Community-wide Guidelines

Benefits/Burdens of Tube Feeding/PEG Placement for Adults

	Dysphagic Stroke (Patients with previous good quality of life, high functional status[1] and minimal co-morbidities)	Dysphagic Stroke (Patients with decreased level of consciousness, multiple co-morbidities, poor functional status[1] prior to CVA)	Neurodegenerative Disease [e.g., Amyotrophic Lateral Sclerosis (ALS)]	Persistent Vegetative State (PVS)	Frailty (Patients with multiple co-morbidities, poor functional status, failure to thrive and pressure ulcers[2]	Advanced Dementia (Patients needing help with daily care, having trouble communicating, and/or incontinent)	Advanced Cancer (Age is the significant predictor of need in advanced head and neck cancer)[4]	Advanced Organ Failure (Patients with CHF, renal or liver failure, COPD, anorexia-cachexia syndrome)
Prolongs Life	*Likely*	*Likely in the short term* Not likely in the long term	*Likely*	*Likely*	Not Likely	Not Likely	Not Likely	Not Likely
Improves Quality of Life and/or Functional Status	up to 25% regain swallowing capabilities	Not Likely	Uncertain	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely
Enables Potentially Curative Therapy/Reverses the Disease Process	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely

This grid reflects only certain conditions. Some examples of other conditions where direct enteral feeding would be indicated include radical neck dissections, esophageal stenosis and motility diseases, post intra-thoracic esophageal surgery and safer nutrition when the alternative would be parenteral hyperalimentation.

Benefits of PEG placement rather than feeding orally:

- For dysphagic stroke patients in previous good health, patients with ALS, and patients in a persistent vegetative state, may prolong life
- For dysphagic stroke patients in previous poor health, may prolong life in the short-term (days to weeks)
- Enables family members/caregivers to maintain hope for future improvement
- Enables family members/caregivers to avoid guilt/conflict associate with choosing other treatment options
- Allows family/caregivers additional time to adjust to possibility of impending death

Burdens of PEG placement rather than feeding orally:

- 75% of stroke patients previously in good health not likely to have improved quality of life and/or functional status
- PVS patients not likely to have improved quality of life and/or functional status
- Possible patient agitation resulting in use of restraints
- Risk of aspiration pneumonia is the same or greater than that of patient being handfed
- Stroke patients previously in poor health, frail patients, and patients w/advanced dementia, cancer or organ failure have been reported to experience side effects: PEG site irritation or leaking (21%), diarrhea (22%), nausea (13%) and vomiting (20%)

Benefits of feeding orally rather than inserting a PEG:

- Patient able to enjoy the taste of food
- Patient has greater opportunity for social interaction
- Patient's wishes and circumstances can be taken into consideration as pertains to pace, timing and volume of feeding

Burdens of feeding orally rather than inserting a PEG:

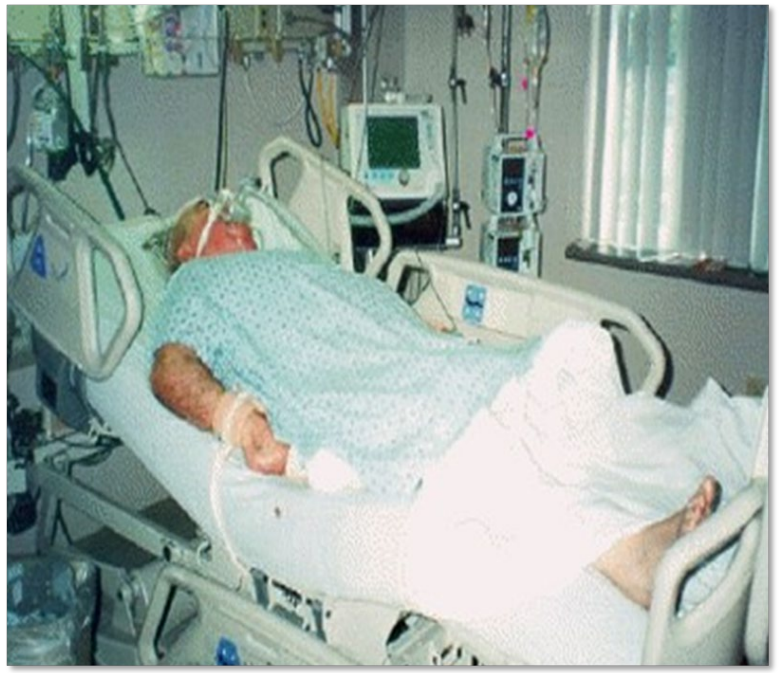
- Requires longer period of time to feed a patient
- Patient/family worry about "not doing everything in their power" to address the feeding problem and/or "starving patient"
- Patient/family feel that in not choosing option that could possibly prolong life, they are hastening death

This information is based predominately on a consensus of current expert opinion. It is not exhaustive. There are always patients who prove exceptions to the rule.

1. Functional Status refers to Activities of Daily Living. For more information on the CFS visit http://geriatricresearch.medicine.dal.ca/clinical_frailty_scale.htm) A poor functional status means full or partial dependency in bathing, dressing, toileting, feeding, ambulation, or transfers.
2. Matched residents with and without a PEG insertion showed comparable sociodemographic characteristic, rates of feeding tube risk factors, and mortality. Adjusted for risk factors, hospitalized NH residents receiving a PEG tube were 2.27 times more likely to develop a new pressure ulcer (95% CI, 1.95-2.65). Conversely, those with a pressure ulcer were less likely to have the ulcer heal when they had a PEG tube inserted (OR 0.70 [95% CI, 0.55-0.89]). Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding Tubes and the Prevention or Healing of Pressure Ulcers. Archives of internal medicine. 2012;172(9):697-701. doi:10.1001/archinternmed.2012.1200.
3. Callahan CM, Haag KM, Weinberger M, et.al. Outcomes of Percutaneous Endoscopic Gastrostomy among Older Adults in a Community Setting. J Am Geriatr Soc. 2000 Sep; 48(9):1048-5
4. Sachdev, S., Refaat, T., Bacchus, I.D. et al. Age most significant predictor of requiring enteral feeding in head-and-neck cancer patients. Radiat Oncol 10, 93 (2015).

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, FHCDA 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

Key Points

MOLST requires thoughtful discussion that ensures well informed shared decision-making.

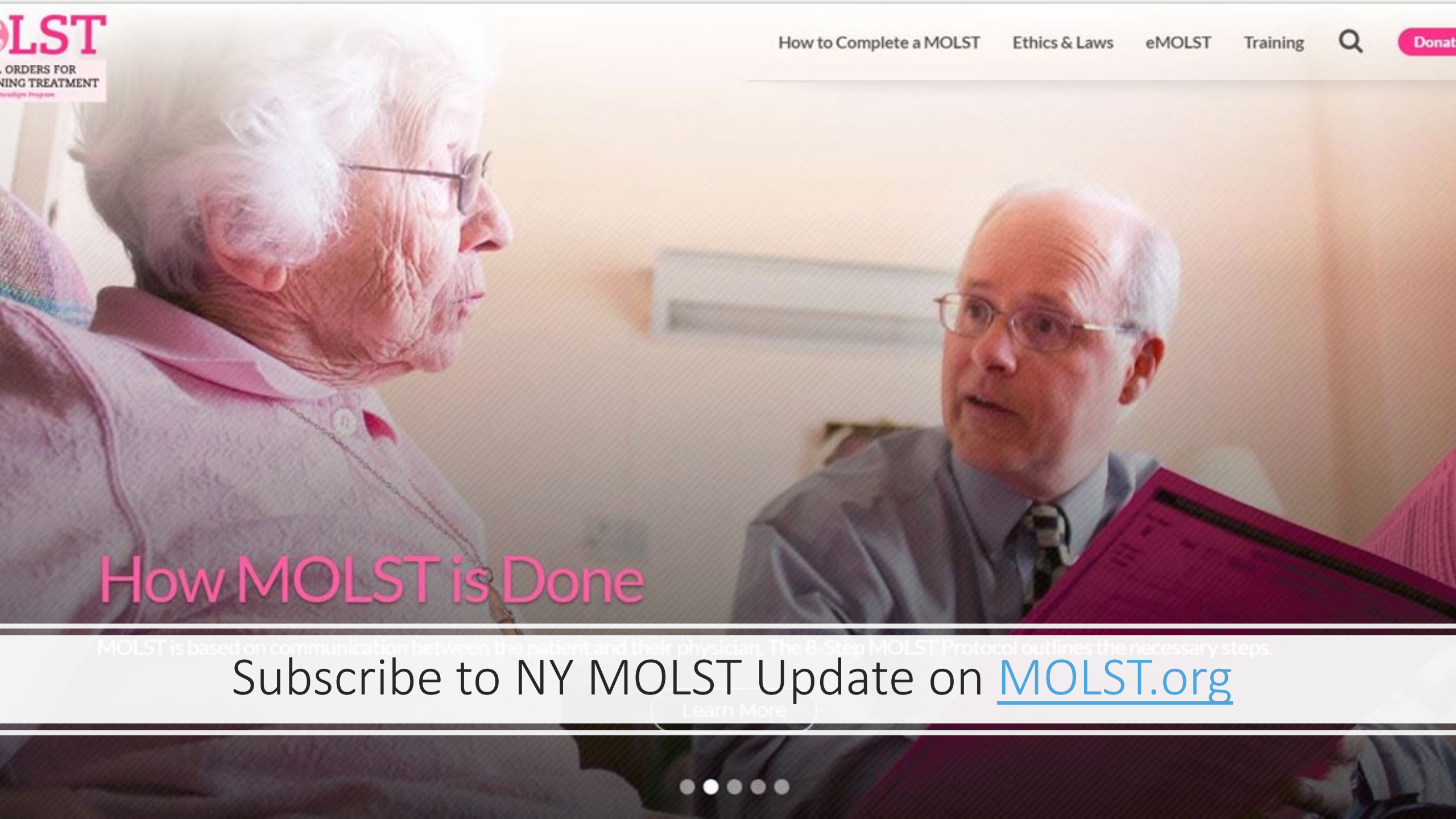
Physicians, NPs (as of 2018 for FHCDA & 2019 for HCP law) and PAs (as of 6/17/2020) have authority and are accountable for accurate completion of MOLST .

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.

Resources



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/ClTAG19RX8w

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

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