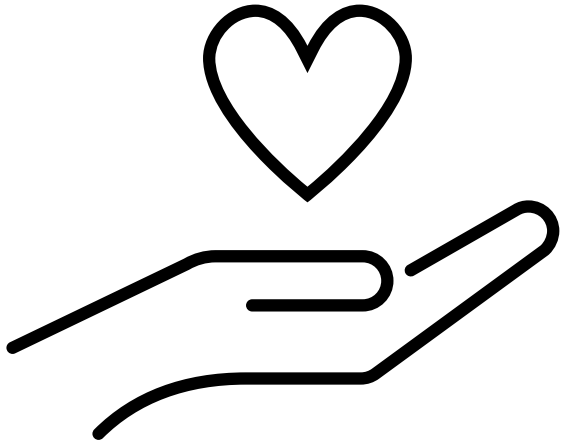

ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)

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

HHN HUDSON HEADWATERS HEALTH NETWORK

The Arc New York

Session 7
Addressing Feeding Challenges

Presenters

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

Learning Objectives

- Review an approach to an individual unable to maintain nutrition
- Recognize the benefits and burdens of feeding tubes in an individual patient
- Explain the determination and proper documentation of necessary medical criteria for decisions to withhold/withdrawal artificially provided nutrition or hydration

Why are Discussions Related to Feeding Difficult for Everyone

Discussions Related to Feeding are Difficult

- Culture
  - Throughout our life, we show our love through food
  - Food is essential element at holidays, celebrations and family events
  - Food is associated with pleasure
- Patients may stop eating, especially patients with advanced illness/frailty
  - Families become distressed
  - Physicians may start artificial feeding even if it will not help and often causes more harm than good

Key Elements for Patient, Family, Surrogate Discussion

Focus	Focus on the underlying disease process as cause of decline and loss of appetite
Emphasize	Emphasize active nature of providing comfort care
Recognize	Recognize concerns about “starvation”, inadequate nutrition or hydration and potentially hastening death that many individuals deal with in facing this decision and address these issues
Clarify	Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food and drink

An Approach to An Individual Unable to Maintain Nutrition

Community-wide Clinical Guidelines on Percutaneous Endoscopic Gastrostomy (PEGs)/Tube Feeding

Developed in 2004; reviewed every 2 years; last review 2022

Rochester Community data

- rising numbers of PEGs
- goals for care discussion not consistently done
- reevaluation did not occur

Goals for Guidelines

- ensure shared informed medical decision-making
- ensure patient goals for care guide choice of interventions
- support the MOLST program

Long Term Feeding Tube Guidelines

Complete a Global Assessment

Identify	Identify potentially reversible causes
Attempt	Attempt corrective action
Initiate	If no response, initiate family discussion

Triggers for Global Assessment of Eating, Feeding & Nutrition

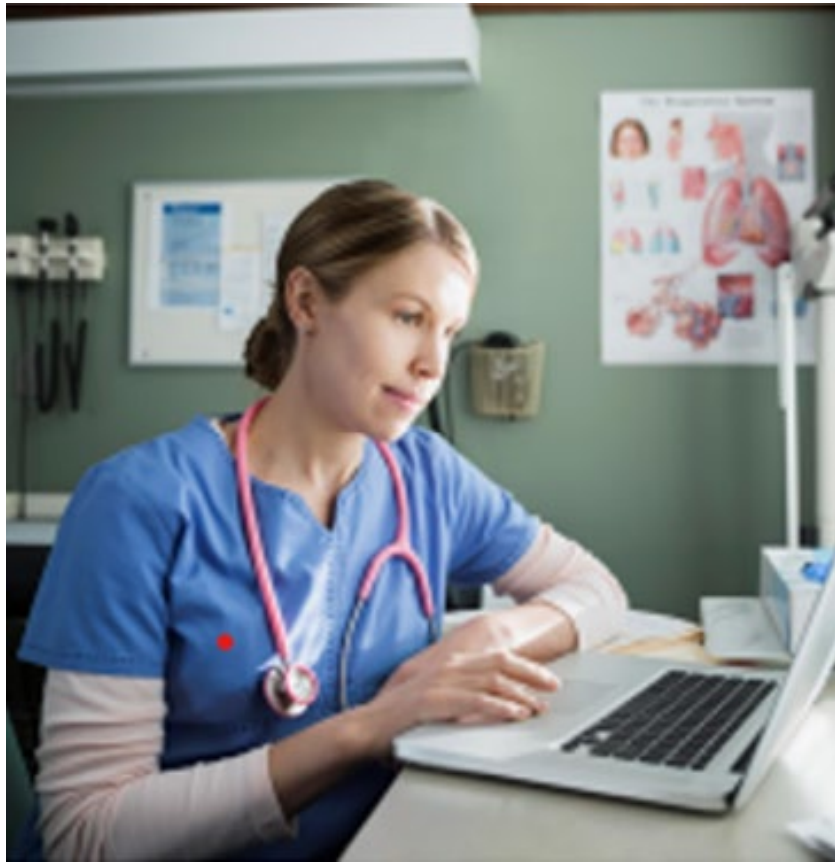
- Weight loss
- Decreased eating (> 25 % left uneaten after most meals)
  - NOTE: Clinicians often overestimate % eaten
- Pressure ulcers
- Presence of enteral or parenteral feedings
- Apparent aspiration and/or dysphagia following, or in the setting of acute illness

Assess Parameters of Nutritional Status

- Weight change (1-2% or more in 1 week, 5% or more in one month, 7.5% or more in 3 months, 10% or > in 6 months)
- Account for possible fluid imbalance
- Body mass index < 18.5 KG/meter squared
- Abnormal lab tests: albumin, pre-albumin, cholesterol, lymphocyte count

Global Assessment: Identify Factors that Impede Ability to Take In Adequate Amounts of Food

- Physical limitations, visual problems
- Chewing problems (problems with mouth, teeth, dentures)
- Swallowing problems (feeding position, consistencies, bolus size, conducive environment, stimulus to swallow: verbal and tactile)
- Conditions that decrease nutrient intake (nausea, vomiting, constipation, cancer, shortness of breath, weakness)
- Alterations in taste secondary to medications, dry mouth, food options



Medical Assessment

- Identify Additional Problems in Relation to Nutritional Status
  - Mental: dementia, depression, anxiety, delusions, apathy
  - Communication problems: inability to make needs known
  - Neurologic Condition
- Perform Medical Assessment
  - Stage of illness, prognosis, pain
  - Assess for constipation/fecal impaction
  - Adverse medication effects
- Assess Hydration Status

Benefits and Burdens of Feeding Tubes

Practical Approach to Discussing Feeding Tubes

Appreciate and respond to emotional cues

Base the conversation on disease specific medical evidence

Key Elements for Patient, Family, Surrogate Discussion

Review health status, prognosis, patient values, beliefs, goals of care

Recognize decreased nutrition is a marker for progressive illness

Describe the disease specific evidence base medicine for PEG tubes

Decision to initiate tube feeding should align with patient goals

Define periodic reassessment as critical

- Benefits/failures are likely to occur in 3 – 6 months
- Focus on the achievement of specific goals of therapy identified with initial PEG placement

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?

Benefits and Burdens

Vary depending upon the individual's

- current medical problems
- health status

Assess benefits and burdens

- enabling an individual to live longer
- have an improved quality of life and/or functional status
- reverse the disease process or enable potentially curative therapy to occur

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).

Advanced Illness including Advanced Frailty

Dysphagic Stroke
- previous good QOL, high functional status, minimal co-morbidities

Dysphagic Stroke
- decreased LOC, multiple comorbidities, poor functional status

Neurologic Disease
- ALS

Persistent Vegetative State

Frailty
- multiple comorbidities, poor functional status, failure to thrive, pressure sores

Advanced Dementia

Advanced Cancer
- head and neck cancer

Advanced Organ Failure
- CHF, renal, liver, COPD, anorexia-cachexia syndrome

Patients with Advanced Dementia

Don’t recommend percutaneous feeding tubes in patients with advanced dementia

Instead, offer oral assisted feeding as tolerated

#1 among top 5 recommendations by AGS, AMDA and AAHPM

Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: A review of the evidence. JAMA. 1999;282(14):1365-1370
See References. Guidelines for Long-Term Feeding Tube Placement, 2004; latest review 2022
Choosing Wisely Recommendations

Feeding Tube Use in Patients with Advanced Dementia

DOES NOT

- result in improved survival
- prevent aspiration pneumonia
- improve healing of pressure ulcers

DOES

- correlate with pressure ulcer development
- increase physical and pharmacological restraints
- cause patient distress about the tube itself

Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: A review of the evidence. JAMA. 1999;282(14):1365-1370

See References. Guidelines for Long-Term Feeding Tube Placement, 2004; latest review 2022

PEG Tubes and Pressure Sores

Matched hospitalized NH residents with and without a PEG insertion

- Comparable sociodemographic characteristic, rates of risk factors, and mortality

Results adjusted for risk factors

- Those receiving a PEG tube were 2.27 times **more** likely to develop a new pressure ulcer
- Those with a pressure ulcer were **less** likely to have the ulcer heal when they had a PEG tube inserted

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.

Necessary Medical Criteria to WH/WD Feeding Tubes

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)

Feeding Tube Trials

Whether or not a new checklist is required following an unsuccessful trial of LST depends on the parameters of the trial, as specified in Step 2 of the checklist.

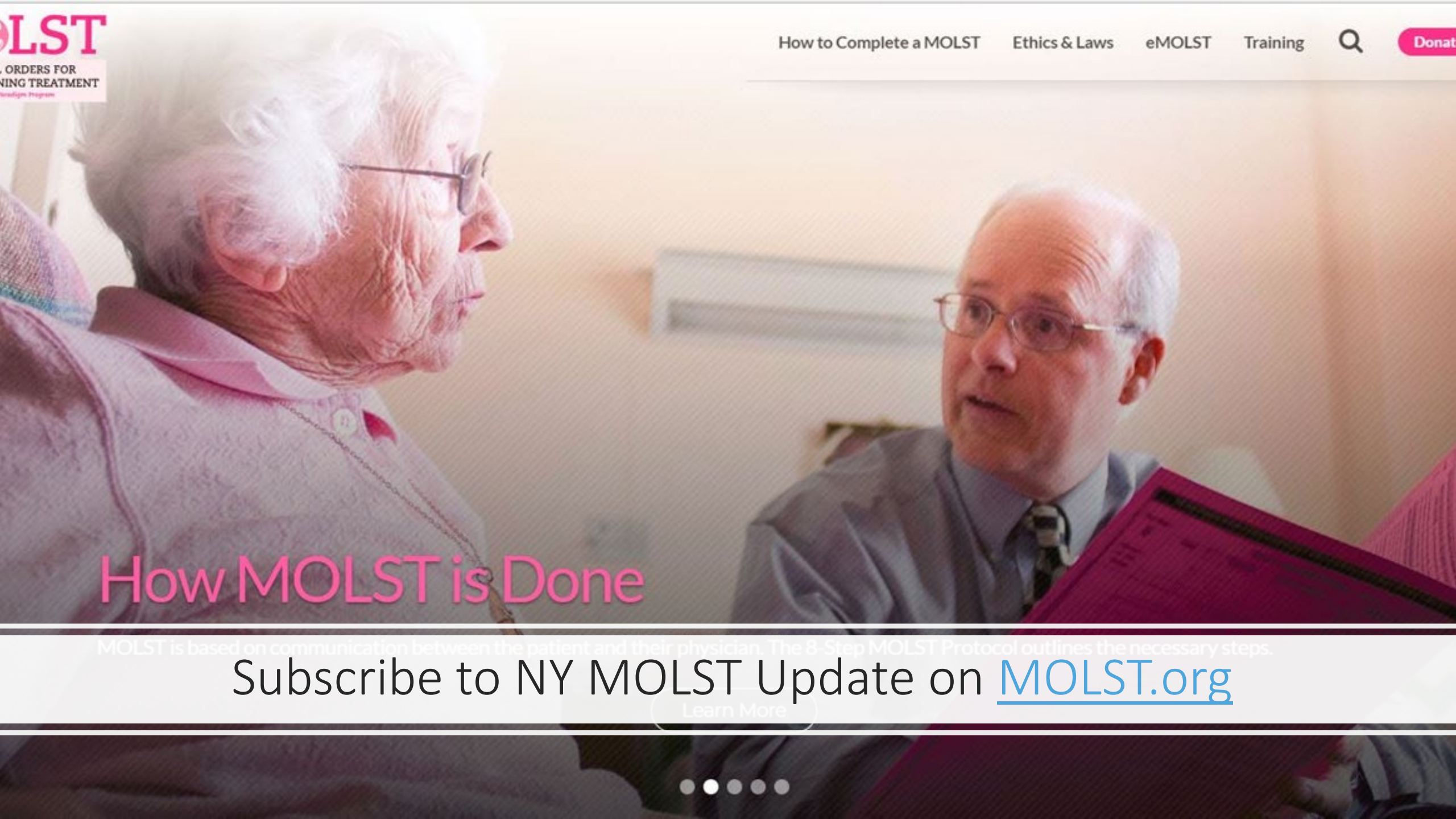
If Step 2 of the checklist has provided that a trial for LST is to end after a specific period of time or the occurrence of a specific event, it may not be necessary to complete a new checklist following the trial.

However, if a trial period is open ended, and the authorized surrogate subsequently decides to request withdrawal of the LST, a new checklist would be required.

Key Points

- Discussions related to feeding are difficult.
- It is critical to do a global assessment of eating, feeding and nutrition.
- In discussing feeding, appreciate and respond to emotional cues.
- Base the discussion on disease specific medical evidence using a shared decision-making model.
- Recognize and document the necessary medical criteria to WH/WD feeding tubes.
- Reevaluate every 3 months and base trials on the person's goals for care.
- Remember, benefits & failures are likely to occur in 3 – 6 months.

Resources



Subscribe to NY MOLST Update on MOLST.org

Videos With Short Videos on AHN

Patient & Family Education

Discussing Feeding Tubes and Artificial Hydration & Nutrition

https://youtu.be/6fNcxIh5mxE

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

Demonstrating Thoughtful MOLST Discussions

Demonstrating Discussion on Feeding Tubes and IV Fluids

https://youtu.be/_dSZ3UGAlwI

Hospital & Hospice Settings

Nursing Home Setting

CompassionAndSupportYouTubeChannel (ACP/MOLST video playlists)

http://www.youtube.com/user/CompassionAndSupport?feature=mhee

References on Feeding Tubes and AHN

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- Fischberg, D., et al. 2013. “Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine.” Journal of Pain and Symptom Management 45(3): 595–605.
- Teno JM, Gozalo P, Mitchell S, Kuo S, Fulton A, Mor V. Feeding Tubes and the Prevention or Healing of Pressure Ulcers. Arch Intern Med. 2012;172(9):697-701.
- Teno JM, Mitchell SL, Gozalo PL, et al. Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. Journal of the American Medical Association. 2010; 303:544-550.
- Additional References Compiled for the Community-Wide Feeding Tube Guidelines
- Choosing Wisely Recommendations
- Health Care Decisions OPWDD webpage: https://opwdd.ny.gov/providers/health-care-decisions
- More at Resources on MOLST.org