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

<table>
<thead>
<tr>
<th><strong>Focus</strong></th>
<th>Focus on the underlying disease process as cause of decline and loss of appetite</th>
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<tbody>
<tr>
<td><strong>Emphasize</strong></td>
<td>Emphasize active nature of providing comfort care</td>
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<tr>
<td><strong>Recognize</strong></td>
<td>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</td>
</tr>
<tr>
<td><strong>Clarify</strong></td>
<td>Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food and drink</td>
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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
**Complete a Global Assessment**

<table>
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<tr>
<th>Identify</th>
<th>Identify potentially reversible causes</th>
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<tbody>
<tr>
<td>Attempt</td>
<td>Attempt corrective action</td>
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<tr>
<td>Initiate</td>
<td>If no response, initiate family discussion</td>
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</table>
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?
  - Will treatment help or harm the patient?

- 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

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

<table>
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<tr>
<th>Benefits of PEG placement rather than feeding orally</th>
<th>Burden of PEG placement rather than feeding orally</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>- 75% of stroke patients previously in good health do not have improved quality of life and/or functional status</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>- PEG patients not likely to have improved quality of life and/or functional status</td>
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<tr>
<td>- Enables family members/caregivers to maintain hope for future improvement</td>
<td>- Risk of aspiration pneumonia is the same or greater than that of the patient being handled</td>
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<tr>
<td>- Enables family members/caregivers to avoid guilt/conflict associated with choosing other treatment options</td>
<td>- Stroke patients previously in poor health, frail patients, and patients w/advanced dementia, cancer or organ failure have been experienced side effects. PEG site irritation or leaking (2.1%), diarrhea (14.7%), nausea (16.7%), and vomiting (20%)</td>
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### 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 pertinent to time, place, and volume of feeding

### Burden of Feeding orally rather than inserting a PEG

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

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


2. Most studies report that a PEG tube is preferred by patients who require tube feeding and are likely to live longer. Several studies have shown that tube feeding is associated with a higher quality of life than alternative nutrition methods. A systematic review of randomized controlled trials found that patients with advanced cancer who receive tube feeding have a better quality of life than those who receive alternative nutrition methods. (Cochrane Database Syst Rev. 2013;3:CD004477. doi: 10.1002/14651858.CD004477.pub3)


<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
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<tr>
<td>Dysphagic Stroke</td>
<td>• previous good QOL, high functional status, minimal co-morbidities</td>
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<tr>
<td>Dysphagic Stroke</td>
<td>• decreased LOC, multiple comorbidities, poor functional status</td>
</tr>
<tr>
<td>Neurologic Disease</td>
<td>• ALS</td>
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<tr>
<td>Persistent Vegetative State</td>
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<tr>
<td>Frailty</td>
<td>• multiple comorbidities, poor functional status, failure to thrive, pressure sores</td>
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<tr>
<td>Advanced Dementia</td>
<td></td>
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<tr>
<td>Advanced Cancer</td>
<td>• head and neck cancer</td>
</tr>
<tr>
<td>Advanced Organ Failure</td>
<td>• CHF, renal, liver, COPD, anorexia-cachexia syndrome</td>
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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

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


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

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)
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
How MOLST is Done

MOLST is based on communication between the patient and their primary care provider. The 8-Step MOLST Protocol outlines the necessary steps.

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

- 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](https://opwdd.ny.gov/providers/health-care-decisions)
- More at [Resources](#) on MOLST.org