

Tube Feeding/PEG Placement for Adults

Purpose

To provide data, information and tools to physicians, other clinicians, patients and families to help fully inform the evaluation and shared decision-making process around the use of tube feeding/PEG placement for the adult population, including persons with developmental disabilities, given the health status, prognosis, values, beliefs and goals for care of the individual patient.

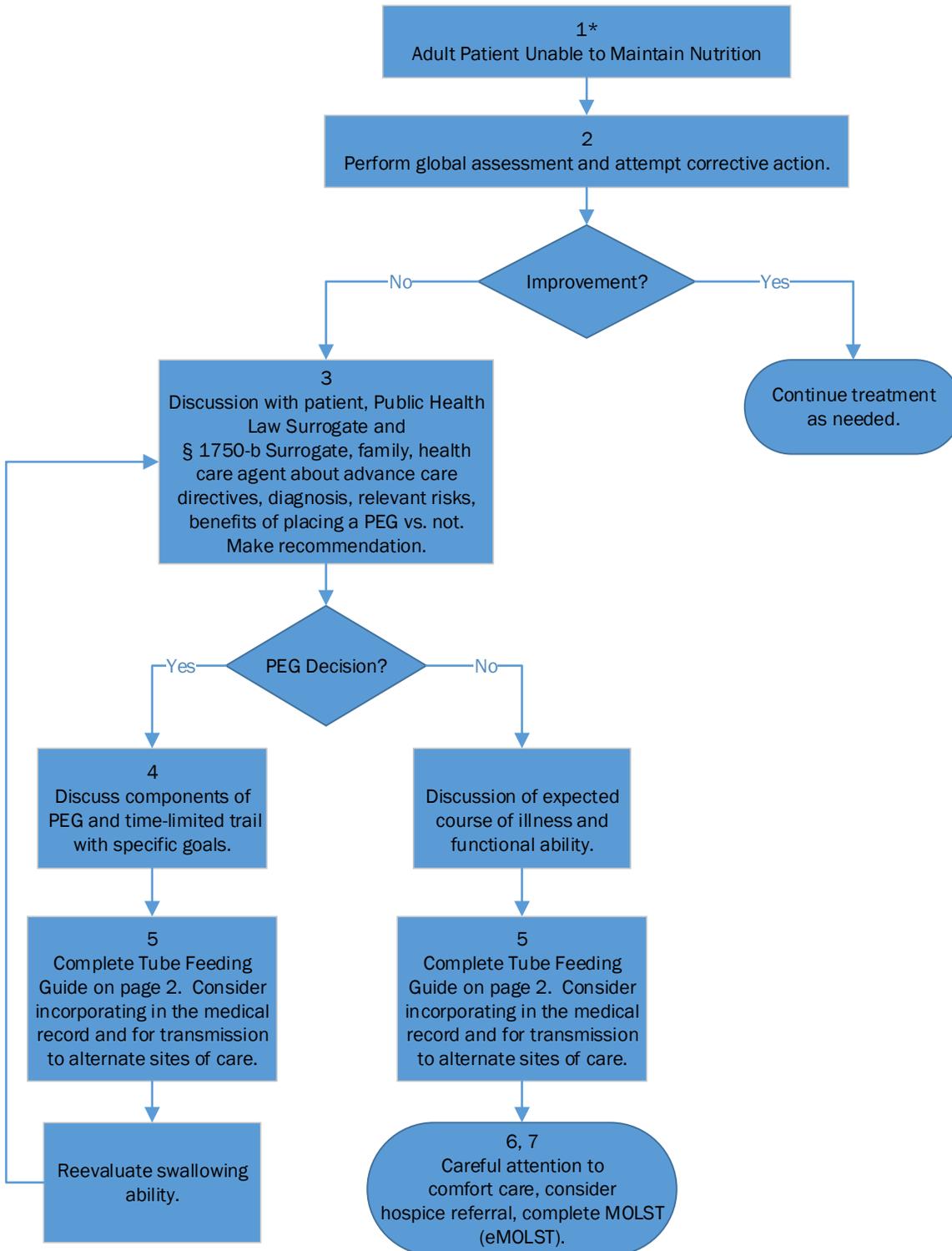
Key Recommendations

- Tube feeding decisions should be guided by principles of shared decision-making:
 1. **Begin** by identifying that there is a feeding tube decision to be made
 2. **ASK** – about the patient and family views and experience with current feeding and feeding tubes
 - a. clarify values and preferences
 - b. explore prior experiences
 - c. understand the meaning of the main approaches to the patient and family
 - d. share and explore any prior knowledge of the patient’s past or present wishes in this regard
 3. **TELL** - the clinician then shares his or her experience, including
 - a. medical knowledge about the patient’s disease process and prognosis
 - b. the ability of a feeding tube to alter the disease process and prognosis
 - c. the alternative approach to tube feeding
 - d. any knowledge of the patient’s past values if incapacitated
 4. **ASK** – if there is information that needs more clarification, or if patient/family have questions about what they have heard
 5. **ASK** - the patient and family should be asked what they think the best approach is given information above
 - a. if the clinician agrees, he or she should let it be known that they agree
 - b. if the clinician disagrees, he or she might ask them to say how they came to that conclusion
 6. **ASK** – if the family would like to know what the clinician would recommend based on his or her medical knowledge and knowledge of the patient as a person
 - a. the clinician should ask if they would like to hear what he or she recommends
 - b. if they want to know, the clinician should make a recommendation based on medical knowledge about feeding tubes in the patient’s medical circumstances in light of what is known about the patient’s values
 - c. if they do not want to know, the clinician should offer to talk to them about it in the future if they would like to know
 - d. differences of opinion should be respectfully and carefully negotiated looking for common ground
 - e. a final decision should be postponed until common ground is established (if differences seem unresolvable, then consider a palliative care or ethics consult)
- If tube feeding is elected, develop specific goals and time intervals for reviewing whether these goals have been achieved.
- Physicians should consider the following questions before ordering a swallowing evaluation:
 1. How was the patient swallowing before the hospitalization?
 2. Will the swallow evaluation make a difference for the patient and change the treatment plan?
- Clinicians providing a swallowing evaluation should consider addressing the following questions for follow-up discussions with physicians:
 1. What recommendations do you have about lessening the risk of aspiration while feeding?
 2. What recommendations do you have about food preparation to lessen aspiration risk?
 3. What recommendations do you have about feeding technique to lessen the risk of aspiration?
 4. Will tube feeding eliminate or even lessen the risk of aspiration when comported with careful oral feeding?
 5. What recommendations do you have about making feeding as enjoyable as possible for the patient?

Tube Feeding/PEG Placement for Adults

Approach to Adult Patient Unable to Maintain Nutrition

*Numbers refer to Flow Chart Reference Sheet on page 4



Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs.

Flow Chart Reference Sheet

1. **Triggers for 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

2. **Global Assessment (see Checklist for Global Assessment):**

➤ **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 of < 18.5 KG/meter squared
- Abnormal lab tests (albumin, pre-albumin, cholesterol, lymphocyte count)

➤ **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

➤ **Identify Additional Problems in Relation to Nutritional Status**

- Mental (dementia, depression, anxiety, delusions, apathy)
- Communication problems resulting in inability to make needs known
- Neurologic conditions

➤ **Perform Medical Assessment**

- Stage of illness, prognosis, pain
- Assess for constipation/fecal impaction
- Adverse medication effects
 - Address the use of medications that can adversely affect either the ability to eat or the desire to do so. Classes of such drugs include those that induce dry mouth, decrease attentiveness, provoke movement disorders and/or cause GI distress of esophagitis.
 - Specific drugs might include:
 - ❖ sedatives: lorazepam; clonazepam, etc.
 - ❖ antipsychotics: risperidone, quetiapine, aripiprazole, etc.
 - ❖ cholinergic drugs for Alzheimer's: donepezil, galantamine, rivastigmine; anticholinergics: tolterodine, oxybutynin chloride
 - ❖ GI irritants or anorexigenics: NSAIDs, COX II, bisphosphonates, opioids, digoxin, theophylline, antibiotics, iron, calcium, memantine, SSRIs

➤ **Assess Hydration Status**

- Urine output
- Orthostatic hypotension

3. **Assessment of Knowledge, Values and Goals:**

➤ **Conversation with Relevant Individuals Should Include Discussion of**

- their understanding of current illness, health status, functional ability
- advance directives or what the patient/individual would want if able to communicate
- hopes and concerns about future course of illness
- patient values, preferences, cultural and spiritual concerns
- general goals for care (not technical options)
- all viable options for addressing nutritional problems
- placement, operation, care required of PEG
- for particular condition, proven benefits and burdens (and the likelihood of both) of placing PEG (**see Benefits and Burdens grid on page 5**)

4. **Discuss/Describe Components of PEG:**

➤ **Discuss Time-limited Trial with Specific Goals for Care**

- Return to baseline level of consciousness
- Acceptable level of functioning
- Nutritional bridge during an acute illness
- Weight gain
- Healing of pressure sores
- Improved biochemical markers of nutrition

➤ **With All Appropriate Individuals, Discuss Who (and at What Interval) Will Revisit the Decision to Continue the PEG**

5. **Tube Feeding Worksheet (Should be Completed for Each Patient):**

6. **Careful Attention to Comfort Care is Critical:**

- Offer and assist eating if needed but do not force food
- Patient preference should determine type and amount of food
- Excellent mouth care is important.

7. **MOLST (Medical Orders for Life-Sustaining Treatment):**

MOLST is a clinical process designed to facilitate communication between health care professionals and patients with advanced illness (or their Health Care Agent or Public Health Law Surrogate or § 1750-b Surrogate) that facilitates shared informed medical decision-making. The result is a set of portable medical orders documented on a bright pink MOLST form that is applicable in all settings and across care transitions, is reviewable, and respects the patient's goals for care regarding the use of cardiopulmonary resuscitation, intubation and mechanical ventilation, hospitalization, feeding tubes and other life-sustaining interventions. To order MOLST forms and learn about eMOLST, visit CompassionAndSupport.org. To learn more about eMOLST, visit NYSeMOLSTregistry.com.

Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs.

Benefits and Burdens of PEG Placement

	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 (Excludes patients with early stage esophageal & oral cancer)	Advanced Organ Failure (Patients with CHF, renal or liver failure, COPD, anorexia-cachexia syndrome)
Prolongs Life	<i>Likely</i>	<i>Likely in the short term</i> <i>Not likely in the long term</i>	<i>Likely</i>	<i>Likely</i>	Not Likely	Not Likely ³	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

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. (Refer to Clinical Frailty Scale (CFS) on page 8. 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. There is a small group of patients who fall into this category whose life could be prolonged.
4. 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):1048-54.

Legal and Ethical Issues

For patients who CAN make decisions for themselves,	Usual standards of informed consent (or refusal) apply. This applies to persons with developmental disabilities who can decide.	Like with any other procedure, the physician will discuss the pros and cons of a feeding tube with the patient, and, if clinically indicated, the patient can agree to have one or not. If they choose to have a feeding tube at one point in time, they can choose to withdraw it at a later date if it is no longer meeting their goals or needs (provided they still have decision-making capacity). If a patient chooses not to have a feeding tube, food and fluids are offered as tolerated using careful hand feeding.						
For patients who CANNOT make decisions for themselves,	Patient has completed a health care proxy form or has the ability to choose a health care agent. This applies to persons with developmental disabilities.	Formally choosing someone to serve as his/her health care “agent”, the agent is required to make decisions for the patient according to what is known about the patient’s wishes, or, if unknown, according to the patient’s best interests. The agent can make all end-of-life decisions on the patient’s behalf, but the decision must be based on “reasonable knowledge” of the patient’s wishes in the case of withdrawing or withholding of tube feeding. For this reason, it is helpful for the signed health care proxy form to include a statement indicating that conversations have occurred between the patient and the health care agent about artificial hydration and nutrition (tube feeding).						
	Patient has not completed a health care proxy form and the person does not have developmental disability.	The legal standard for withholding or withdrawing a feeding tube is currently different depending upon whether the patient resides in a medical facility (hospital or nursing home) or community (e.g. patient’s home, assisted living facility, etc.). As of September 2011 under New York State law “hospital” means a general hospital or hospice.						
		<p>If such a patient is in hospital or nursing home, New York State law allows for surrogate decision makers to make decisions about tube feeding based upon “substituted judgment” (what is known about, the patient’s wishes), or if unknown based on the patient’s best interests. Surrogate decision makers in NYS are in order of priority:</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;">1. A patient’s authorized guardian</td> <td style="width: 50%;">4. Parent</td> </tr> <tr> <td>2. Spouse (if not legally separated) or domestic partner</td> <td>5. Brother/sister (age 18 or over)</td> </tr> <tr> <td>3. Son or daughter over the age of 18</td> <td>6. Close friend (Must complete a signed statement as a close friend)</td> </tr> </table> <p>Additionally, under this circumstance, two physicians must concur that either:</p> <ol style="list-style-type: none"> i. the patient has an illness or injury expected to cause death within six months, or ii. the patient is permanently unconscious, or iii. treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition <p>Special requirements exist for an Ethics Review Committee to determine that patient-centered and clinical standards are met:</p> <ol style="list-style-type: none"> i. In a hospital, <u>other than a hospice</u>, if the attending physician disagrees with a decision to withhold or withdraw a feeding tube ii. In a nursing home, for all life-sustaining treatment, including a feeding tube, if the clinical standard that the patient meets is “treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition”. 	1. A patient’s authorized guardian	4. Parent	2. Spouse (if not legally separated) or domestic partner	5. Brother/sister (age 18 or over)	3. Son or daughter over the age of 18	6. Close friend (Must complete a signed statement as a close friend)
1. A patient’s authorized guardian	4. Parent							
2. Spouse (if not legally separated) or domestic partner	5. Brother/sister (age 18 or over)							
3. Son or daughter over the age of 18	6. Close friend (Must complete a signed statement as a close friend)							
		<p>If the patient in a hospital or nursing home has not completed a health care proxy form and no surrogate from the list is available, decisions about withholding or withdrawing tube feeding can be made if two physicians concur that:</p> <ol style="list-style-type: none"> i. life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND ii. the provision of life sustaining treatment would violate accepted medical standards 						
		<p>If the patient has not completed a health care proxy form and is not in hospital or nursing home, the legal standard for making a decision about withholding or withdrawing of feeding tubes is “clear and convincing evidence” of the patient’s wishes. A prior written statement about feeding tubes or artificial nutrition in a Living Will, completion of the New York State Medical Orders for Life Sustaining Treatment (MOLST) or clear prior oral statements by the patient about his or her wishes may provide “clear and convincing evidence.”</p>						
	Patient has not completed a health care proxy form, does not have the ability to choose a health care agent and the person has developmental disabilities.	<p>Physicians must follow the § 1750-b process as outlined on the MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities. Two physicians must determine to a reasonable degree of medical certainty that both of the following conditions are met: (1) the individual has one of the following medical conditions: a. a terminal condition; (briefly describe); or b. permanent unconsciousness; or c. a medical condition other than DD which requires LST, is irreversible and which will continue indefinitely (briefly describe) AND (2) the LST would impose an extraordinary burden on the individual in light of: a. the person’s medical condition other than DD (briefly explain) and b. the expected outcome of the LST, notwithstanding the person’s DD (briefly explain.) If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn or withheld, one of the following additional factors must also be met: a. there is no reasonable hope of maintaining life (explain); or b. the artificially provided nutrition or hydration poses an extraordinary burden (explain.)</p>						

**Approach to Adult Patient Unable to Maintain Nutrition
Checklist for Global Assessment**

Patient Name

Date of Birth

Check each factor considered/addressed

Parameters of Nutritional Status

- Weight Change
- Body Mass Index
- Lab Tests: albumin, prealbumin, cholesterol, lymphocyte count
- Hydration Status (skin turgor, heart rate, BUN/creatinine)
- Urine Output
- Other: _____

Comments about above factors: _____

Factors that Impede Ability to Take in Food

- Physical Limitations
- Pain
- Visual Problems
- Chewing Problems: mouth, teeth, dentures
- Swallowing Problems: cough after/while eating, holding bolus, pocketing, position while eating or being fed
- Nausea/Vomiting
- Constipation
- Candidiasis
- Shortness of Breath
- Dementia, Depression, Anxiety
- Communication Problems
- Neurological Conditions
- Other: _____

Comments about above factors: _____

Medical Assessment

- Stage of Illness : advanced or end stage illness
- ADL Score (please refer to Appendix G for Clinical Frailty Scale): current _____
- ADL Score: 1 month prior to admission _____
- Constipation/Fecal Impaction
- Other: _____

Comments about above factors: _____

Potential Problem Medications

- Sedatives: lorazepam, clonazepam, etc.
- Antipsychotics: risperidone, quetiapine, aripiprazole, etc.
- Cholinergics for Alzheimer's and other dementias: donepezil, galantamine, rivastigmine
- Anticholinergics: tolterodine, oxybutynin chloride
- GI irritants or anorexigencis: NSAIDs, COX IIs, bisphosphonates, opioids, digoxin, theophylline, antibiotics, iron, calcium, memantine, SSRIs
- Other: _____

Comments about medications: _____

Correctable Conditions Identified and Acted Upon and Additional Comments:

Evaluating Clinician:

Name

Initials

Date

Tube Feeding/PEG Placement for Adults

Clinical Frailty Scale*

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 minimal assistance (cuing, standby) with dressing.



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.

*Clinical Frailty Scale (CFS)[®] Geriatric Medicine Research, Dalhousie University, Halifax, Canada. Permission granted to copy the Clinical Frailty Scale for research and educational purposes only. For more information on the CFS, visit http://geriatricresearch.medicine.dal.ca/clinical_frailty_scale.htm.

Tube Feeding/PEG Placement for Adults

Resources for Physicians

American Geriatrics Society

- o Position Statement - Feeding Tubes in Advanced Dementia (2014)

Choosing Wisely®

Choosing Wisely® is an initiative of the American Board of Internal Medicine Foundation to help clinicians and patients engage in conversations to reduce overuse of tests and procedures, and support patients in their efforts to make smart and effective care choices. More than 70 specialty society partners have released recommendations with the intention of facilitating wise decisions about the most appropriate care based on a patients' individual situation.

- o The American Academy of Hospice and Palliative Medicine and the American Geriatric Society listed this recommendation as #1 of their top 5 in 2013, the first year of the Choose Wisely Campaign:
***Don't RECOMMEND percutaneous feeding tubes in individuals with advanced dementia.
Instead, offer oral assisted feedings.***
- o The American Medical Directors Association – The Society for Post-Acute and Long-Term Care Medicine (AMDA) listed this recommendation as #1 of their top 5 in 2013, the first year of the Choose Wisely Campaign:
***Don't INSERT percutaneous feeding tubes in individuals with advanced dementia.
Instead, offer oral assisted feedings.***

CompassionAndSupport.org

Educates and empowers patients, families and professionals on issues related to advance care planning, health care proxies, MOLST (Medical Orders for Life Sustaining Treatment), palliative care, and pain management.

- o Feeding Tubes & Artificial Nutrition & Hydration - addresses the benefits, burdens and challenges of artificial hydration/ nutrition and feeding tubes.
- o MOLST for Professionals
- o **MOLST Chart Documentation Forms (CDFs align with NYSDOH Checklists)**
- o Documentation of the clinical process and legal requirements must be included in the medical record. Completion of the appropriate MOLST Chart Documentation Form serves as documentation of both the conversation and the legal requirements and should remain in the medical record.
 - o MOLST CDF aligns with DOH Checklist #1: <http://goo.gl/f09m4>
 - o MOLST CDF aligns with DOH Checklist #2: <http://goo.gl/oyxsr>
 - o MOLST CDF aligns with DOH Checklist #3: <http://goo.gl/jUkOd>
 - o MOLST CDF aligns with DOH Checklist #4: <http://goo.gl/XdKEK>
 - o MOLST CDF aligns with DOH Checklist #5: <http://goo.gl/eQaVc>
- o OPWDD **MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities:** <http://goo.gl/RP6eO>
- o MOLST Training Center
- o MOLST and eMOLST videos hosted on the CompassionAndSupport Channel on YouTube – educational videos covering changes in New York State Public Health Law, including the 2010 Family Health Care Decisions Act; using the 8-step MOLST protocol; eMOLST; five easy steps and short stories about advance care planning and created playlists.
- o eMOLST website - eMOLST allows for electronic completion of the current New York State Department of Health-5003 MOLST form. By moving the MOLST form to a readily accessible electronic format and creating the New York eMOLST Registry, health care providers, including EMS, can have access to MOLST forms at all sites of care including hospitals, nursing homes and in the community. The New York eMOLST Registry is an electronic database centrally housing MOLST forms and Chart Documentation Forms (CDFs) to allow 24/7 access in an emergency.
- o Patient and Family Stories - describes decision regarding a feeding tube initially inconsistent with the patient's values.

Tube Feeding/PEG Placement for Adults

Resources for Patients

ALS Association

Provides information about feeding tubes for people with ALS and caregivers.

Choosing Wisely®

Choosing Wisely® is an initiative of the American Board of Internal Medicine Foundation to help physicians and patients engage in conversations to help make wise decisions about the most appropriate care based on a patient's individual situation. Consumer Reports is a partner in this effort and works with more than 70 specialty societies to create patient educational material about what care is best for them and the right questions to ask their physicians.

- Information about feeding tubes for people with Alzheimer's. Developed in cooperation with the American Academy of Hospice and Palliative Medicine and the American Geriatrics Society.
 - [English](#) version
 - [Spanish](#) version

CompassionAndSupport.org

Educates and empowers patients, families and professionals on issues related to advance care planning, health care proxies, MOLST, palliative care, and pain management). Videos available:

- [Discussing Feeding Tubes & Artificial Nutrition & Hydration](#) - addresses the benefits, burdens & challenges of artificial hydration & nutrition and feeding tubes.
- [Patient and Family Stories](#) - describes decision regarding a feeding tube initially inconsistent with the patient's values)

Health in Aging Foundation (Foundation of the American Geriatric Society)

Recommendations on the use of feeding tubes in people with advanced dementia.

Handbook for Mortals

Guidance information and key questions for patients and caregivers on tube feedings (fluids and food) – *Why is it sometimes so hard to let a patient go without eating?*

University of North Carolina Palliative Care Program

- [Making Choices: Feeding Options for Patients with Dementia](#) - Decision aid that explains feeding options for people with dementia. (PowerPoint)
- [Helps educate families about feeding problems in people with dementia](#) (video)

Patient/Family/Clinician Information

To Help You Make a Decision About Tube Feeding/PEG Placement

Problems Swallowing/Eating

People who have a serious illness or are weak may sometimes have problems getting the nourishment we think they need for their body to function properly. Eating and/or swallowing become difficult. When this occurs, the doctor will try to find out what is causing the problem. If treatment or changes in the environment can be made to address this problem, the doctor will see that these changes are made. If the problem cannot be addressed through these changes, the doctor will likely talk to the person and his or her family about tube feeding. One tube feed procedure involves placement of a PEG tube, a feeding tube placed through the skin into the stomach through a small hole in the abdomen.

Discussions with the Doctor about Tube Feeding

Before discussing tube feeding fully, the doctor will ask the person who is sick (or their loved ones if that person cannot make a decision for themselves) about whether or not tube feeding is a procedure that they might be interested in. Some people have very strong feelings about tube feeding and often they have discussed their feelings with loved ones. The doctor will ask about whether the sick person has done any advance care planning whether they have completed a health care proxy or living will. The doctor will ask if the person has had any prior discussions with loved ones about health care preferences in situations like these. Making a decision about tube feeding is often a difficult decision.

If you are making this decision for your loved one, it is important to distinguish what it is they would want for themselves if they could decide for themselves, and to separate that wish from what you would wish for them. It is their wish that should form the basis of the decision.

The Tube Feeding Decision

There are many aspects that need to be considered when making a decision about tube feeding. It is important to consider the advantages, disadvantages and other considerations of feeding tube placement. It is also important to look at the advantages, disadvantages and other considerations to continuation of hand feeding.

The questions you might ask in regards to this decision are:

- Will my loved one live longer, or possibly die sooner, as a result of having a PEG tube placed?
- Will the quality of their life improve and will that quality of life be something they would value?
- Will placing a PEG allow for treatment that is likely to cure their underlying illness?

For example, using tube feeding for a person who had a stroke but was in good health prior to having it will lead to different results than using a tube feeding for a person who has Alzheimer's disease.

Emotions often play a large role in the decision to tube feed. Feelings of guilt about "not doing everything in your power" to help the person and pressure from others may affect the decision making process. Finally, personal beliefs regarding tube feeding influence the decision as well. Health care spokespersons and family members have many questions to consider in making a decision about tube feeding. People who choose not to have tube feedings can be kept comfortable with small sips of liquid and lubrication of their mouths and lips. Most patients will not experience greater comfort because of tube feedings being started. Exceptions to this include some patients with acute injuries that impair their ability to swallow and some people with early cancers of the head and neck and esophagus.

If you and your family members have conflicting views about whether or not the person should have a tube feed placed, it is important to ask for help in making the decision. The doctor is available to meet with all family members together if this might be helpful. Perhaps a discussion with the chaplain or faith leader may help as well.

Tube Feeding Procedure

Placing a PEG tube usually takes about 15 minutes. It involves a number of steps. Liquid food is put into a bag that is delivering into the stomach through this tube.

Tube feeding can be done for a limited amount of time. When the decision is made to place the feeding tube, a decision can also be made that the use of the tube will be reviewed in 1 month or 2 or 3 to see if it is still the right thing to do. If it is felt that the original goals of tube feeding are not met, then a new decision can be made to discontinue the tube feeding.

Alternatives to Tube Feeding

Continuing to feed by mouth (feeding orally) is an option to inserting a PEG. Feeding by mouth also has its advantages and disadvantages. Eating allows a person the ability to enjoy the taste of food and have increased social interaction with others. However, is usually requires a longer period of time to feed someone who has problems eating or swallowing.

Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs.

**Patient/Family/Clinician Information
Benefits and Burdens of Tube Feeding/PEG Placement**

GOALS FOR CARE

DISEASES	Prolongs Life	Improves Quality of Life or Functional Ability³	Enables a Cure or Reverses the Disease Process
Stroke (good health in general before this)	Likely	Up to 25% regain ability to swallow	Not Likely
Stroke (in poor health before this)	Likely in the short term	Not Likely	Not Likely
	Not likely in the long term		
Neurodegenerative Disease [for example, Amyotrophic Lateral Sclerosis (ALS)] ¹	Likely	Uncertain	Not Likely
Persistent Vegetative State(PVS) ²	Likely	Not Likely	Not Likely
Advanced Organ Failure	Not Likely	Not Likely	Not Likely
Frailty	Not Likely	Not Likely	Not Likely
Advanced Dementia	Not Likely ⁴	Not Likely ⁴	Not Likely
Advanced Cancer	Not Likely	Not Likely	Not Likely

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

1. A severe disease affecting the brain and spinal cord.
2. Person with severe brain damage with no awareness.
3. Ability to do things like eating, dressing, going to the bathroom without assistance.
4. There is a small group of patients who fall into this category whose life could be extended.

Hoja informativa para el paciente/familia/el clínico
Beneficios y dificultades del Alimentación por tubo/PEG

ETAS PARA EL CUIDADO

ENFERMEDADES	Prolonga la vida	Mejora la calidad de vida o habilidad funcional³	Permite la cura o revierte el proceso de la enfermedad
Derrame cerebral (buena salud en general antes de esto)	Probable	Posibilidad de recuperar la habilidad de tragar de hasta 25%	Poco probable
Derrame cerebral (salud pobre antes de esto)	Probable a corto plazo	Poco probable	Poco probable
	Poco probable a largo plazo		
Neurodegenerativas Esclerosis Lateral [por ejemplo, esclerosis lateral amiotrófica (EAL-ALS en inglés)] ¹	Probable	Incierto	Poco probable
Estado vegetativo persistente (EVP) ²	Probable	Poco probable	Poco probable
Fallo avanzado de los órganos	Poco probable	Poco probable	Poco probable
Debilidad	Poco probable	Poco probable	Poco probable
Demencia avanzada	Poco probable ⁴	Poco probable ⁴	Poco probable
Cáncer avanzado	Poco probable	Poco probable	Poco probable

Esta información se basa principalmente en un consenso de la opinión actual de expertos. De ninguna manera es exhaustiva. Siempre hay pacientes cuya experiencia provee excepciones a la regla.

1. Una enfermedad grave que afecta el cerebro o la médula espinal
2. Persona con daño cerebral grave sin conciencia
3. Habilidad de hacer cosas tales como comer, vestirse, ir al baño sin asistencia
4. Hay un pequeño grupo de pacientes que cae en esta categoría cuya vida puede ser extendida

Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs.

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