

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

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

### **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](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.

These 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. For patients associated with OPWDD a separate process must be followed, see OPWDD checklists.

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).
5. Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding tubes and the prevention or healing of pressure ulcers. Arch Intern Med. 2012 May 14;172(9):697-701. doi: 10.1001/archinternmed.2012.1200. PMID: 22782196; PMCID: PMC3555136.

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**Legal and Ethical Issues**

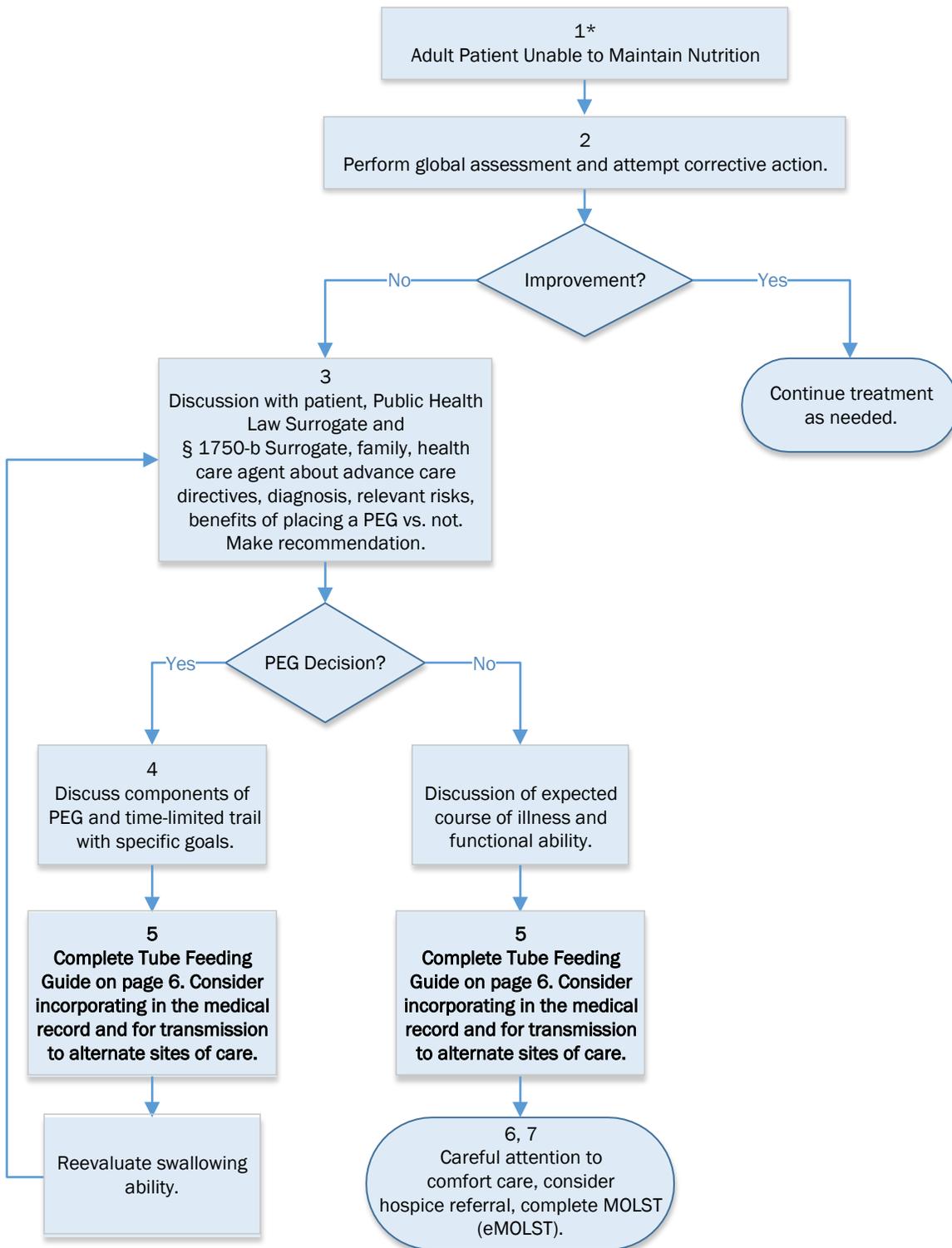
|  |  |   |                                    |           |  |                                    |  |  |
|--|--|---|------------------------------------|-----------|--|------------------------------------|--|--|
| <p>For patients who <b>CAN</b> make decisions for themselves,</p>    | <p><b>Usual standards of informed consent (or refusal) apply. This applies to persons with developmental disabilities who can decide.</b></p>                            | <p>Like with any other procedure, the physician, nurse practitioner or physician assistant 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.</p>   |                                    |           |  |                                    |  |  |
| <p>For patients who <b>CANNOT</b> make decisions for themselves,</p> | <p><b>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.</b></p>  | <p>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).</p>  |                                    |           |  |                                    |  |  |
|  | <p><b>Patient has not completed a health care proxy form and the person does not have developmental disability.</b></p>  | <p>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>   |                                    |           |  |                                    |  |  |
|  |  | <p><b>If such a patient is in hospital or nursing home or hospice,</b><br/>                 New York State law allows for <b>surrogate decision makers to make decisions about tube feeding based upon “substituted judgment”</b> (what is known about, the patient’s wishes), <b>or</b> if unknown based on the patient’s <b>best interests</b>. 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<br/>close friend)</td> <td>6. Close friend (Must complete a signed statement as a close friend)</td> </tr> </table> <p>Additionally, under this circumstance, two physicians or nurse practitioners or physician assistants must concur that either:</p> <ol style="list-style-type: none"> <li>i. the patient has an illness or injury expected to cause death within six months, or</li> <li>ii. the patient is permanently unconscious, or</li> <li>iii. treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition</li> </ol> <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"> <li>i. In a hospital, <b>other than a hospice</b>, if the attending physician or attending nurse practitioner or physician assistant* disagrees with a decision to withhold or withdraw a feeding tube</li> <li>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”.</li> </ol> | 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<br>close friend) | 6. Close friend (Must complete a signed statement as a close friend) |
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| 3. Son or daughter over the age of 18<br>close friend)               | 6. Close friend (Must complete a signed statement as a close friend)   |   |                                    |           |  |                                    |  |  |
|  |  | <p><b>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 or nurse practitioners or physician assistants* concur that:</b></p> <ol style="list-style-type: none"> <li>i. life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND</li> <li>ii. the provision of life sustaining treatment would violate accepted medical standards</li> </ol>  |                                    |           |  |                                    |  |  |
|  |  | <p><b>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 patient in hospice in the community follows the same procedures as in the hospital.</b> 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>   |                                    |           |  |                                    |  |  |
|  | <p><b>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.</b></p> | <p><b>Physicians must follow the § 1750-b process as outlined on the MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities.</b> Two physicians must determine to a reasonable degree of medical certainty that <b>both</b> 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) <b>AND</b> (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>  |                                    |           |  |                                    |  |  |

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## Approach to Adult Patient Unable to Maintain Nutrition

\*Numbers refer to Flow Chart Reference Sheet on page 4



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# 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:**

### ➤ **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

### ➤ **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)

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

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

### ➤ **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 IIs, 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. **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.

## 6. **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 learn more about MOLST, visit [CompassionAndSupport.org](http://CompassionAndSupport.org).

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

### 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 or nurse practitioners or physician assistants\* 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, nurse practitioners or physician assistants\*:
  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 in any way lessen the risk of aspiration during natural feeding?
  5. What recommendations do you have about making feeding as enjoyable as possible for the patient?



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

### Resources for Physicians, Nurse Practitioners and Physician Assistants

#### American Geriatrics Society

- [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.

- 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.***

- 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.***

#### Clinical Frailty Scale (CFS)©

Geriatric Medicine Research, Dalhousie University, Halifax, Canada. Permission granted to copy the Clinical Frailty Scale for research and education purposes only.

For more information on the CFS: <https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale.html>

#### [CompassionAndSupport.org](#)

Anyone can suddenly face serious life-threatening illness and death. People should plan ahead, know their choices, and share their wishes. This can help with making sound decisions. Patients deserve to be treated with dignity, respect and compassion and to receive care that is focused on their goals. Families deserve to receive support.

CompassionAndSupport.org aims to engage, educate and empower patients, families and professionals on issues related to advance care planning, health care proxies, palliative care, and pain management.

#### [MOLST.org](#)

The Medical Orders for Life-Sustaining Treatment (MOLST) program is designed to improve the quality of care seriously ill people receive at the end of life. MOLST is based on the patient's current health status, prognosis, and goals for care. The discussion emphasizes shared medical decision-making that helps the patient understand what can and cannot be accomplished. The result is a set of medical orders that must be honored by all health care professionals in all settings. MOLST.org aims to engage, educate and empower patients, families and professionals on MOLST, New York's endorsed National POLST Paradigm Program. Medical orders related to feeding tubes is included. See <https://molst.org/how-to-complete-a-molst/molst-form/feeding-tubes/>

Authority of Nurse Practitioners under Current NYS Law (2018, 2019) <https://molst.org/ethics-laws/advance-care-planning/authority-of-nurse-practitioners-and-current-nys-law/> Accessed March 19, 2020

Authority of Physician Assistants under Current NYS Law (2020) <https://molst.org/ethics-laws/proposed-legislation/authority-of-physician-assistants-under-current-nys-law/> Accessed March 19, 2020

NYSDOH MOLST Checklists: [https://www.health.ny.gov/professionals/patients/patient\\_rights/molst/](https://www.health.ny.gov/professionals/patients/patient_rights/molst/)

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

[OPWDD MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities](https://opwdd.ny.gov/opwdd_resources/information_for_clinicians/documents/molst-checklist)  
[https://opwdd.ny.gov/opwdd\\_resources/information\\_for\\_clinicians/documents/molst-checklist](https://opwdd.ny.gov/opwdd_resources/information_for_clinicians/documents/molst-checklist)

### Professional Society Statements

American Gastroenterological Association. American Gastroenterological Association Medical Position Statement: Guidelines for the Use of Enteral Nutrition. *Gastroenterology*. 1995;108:1280-1301  
[http://www.gastrojournal.org/article/0016-5085\(95\)90230-9/pdf](http://www.gastrojournal.org/article/0016-5085(95)90230-9/pdf)

American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee Disclosures. *J Am Geriatr Soc*. 2014;62(8):1590-1593.

American Academy of Hospice and Palliative Medicine. Five Things Physicians and Patients Should Question. *Choosing Wisely®* is an initiative of the ABIM Foundation. 2013 Feb. <http://www.choosingwisely.org/societies/american-academy-of-hospice-and-palliative-medicine/>

American Medical Directors Association (AMDA). Altered nutritional status in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA).2010. 35 p. <http://www.guideline.gov/content.aspx?id=32490>

American Medical Directors Association. Ten Things Physicians and Patients Should Question. *Choosing Wisely®* is an initiative of the ABIM Foundation. 2013 September (1-5) and 2015 March (6-10); rationale for #8 updated 2015 July <http://www.choosingwisely.org/societies/amda-the-society-for-post-acute-and-long-term-care-medicine/>

## Benefits/Burdens of 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

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

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

#### **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)

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

### Recursos para pacientes

#### [ALS Association](#)

Esta asociación facilita información sobre las sondas de alimentación a las personas con esclerosis lateral amiotrófica (ELA o ALS, por sus siglas en inglés) y a sus cuidadores.

#### [Choosing Wisely®](#)

*Choosing Wisely®* es una iniciativa lanzada por el American Board of Internal Medicine Foundation (Panel Estadounidense de la Fundación de Medicina Interna) con el objetivo de propiciar la comunicación entre los médicos y los pacientes a fin de que tomen decisiones acertadas con respecto a la asistencia médica más adecuada para cada paciente en función de la situación particular. Consumer Reports colabora en esta iniciativa y trabaja con más de 70 sociedades especializadas con el objeto de crear materiales educativos para los pacientes sobre la atención médica que más se ajusta a sus necesidades y sobre las preguntas que pueden hacer a los médicos.

- Información sobre las sondas de alimentación para personas con la enfermedad de Alzheimer. Documento elaborado en cooperación con la American Academy of Hospice and Palliative Medicine (Academia Estadounidense de Hospicio y Medicina Paliativa) y la American Geriatrics Society (Sociedad Estadounidense de Geriátrica).

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#### [CompassionAndSupport.org](#)

Cualquier persona puede enfrentar repentinamente enfermedades graves que ponen en peligro la vida y la muerte. La gente debe planificar con anticipación, conocer sus decisiones y compartir sus deseos. Esto puede ayudar a tomar decisiones acertadas. Los pacientes merecen ser tratados con dignidad, respeto y compasión y recibir atención enfocada en sus metas. Las familias merecen recibir apoyo. CompassionAndSupport.org tiene como objetivo involucrar, educar y empoderar a los pacientes, familias y profesionales en temas relacionados con la planificación de la atención avanzada, los representantes de atención médica, los cuidados paliativos y el manejo del dolor.

#### [Health in Aging Foundation](#) (Fundación de la Sociedad Estadounidense de Geriátrica)

Esta fundación ofrece recomendaciones sobre el uso de las sondas de alimentación para personas con demencia avanzada.

#### Programa de cuidados paliativos de la Universidad de Carolina del Norte

- [Toma de decisiones: opciones de alimentación para los pacientes con demencia](#): presentación de ayuda para la toma de decisiones que explica las opciones de alimentación disponibles para las personas con demencia (PowerPoint).
- [Información para las familias sobre los problemas de alimentación de las personas con demencia](#) (video).

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

### 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 regard 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 delivered 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, it 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. For patients associated with OPWDD a separate process must be followed, see OPWDD checklists.*

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

### Información para pacientes, familias y médicos clínicos Ayuda para tomar decisiones sobre la alimentación por sonda o colocación de sonda de GEP

#### Dificultad para tragar o comer

Las personas que padecen una enfermedad grave o que tienen una salud frágil a veces tienen dificultad para conseguir los nutrientes que creemos que necesitan para que sus cuerpos funcionen correctamente. Cuando comer o tragar se convierte en una labor difícil, el médico tratará de identificar la causa del problema. Si se pueden realizar tratamientos o ajustes en el entorno para solucionar este problema, el médico se asegurará de tomar las medidas necesarias. Si el problema no se puede solucionar a través de dichas medidas, lo más probable es que el médico hable con el paciente y su familia sobre la posibilidad de usar una sonda de alimentación. Un procedimiento de alimentación por sonda conlleva la colocación de una sonda de GEP (gastrostomía endoscópica percutánea); esto es, una sonda de alimentación que se introduce en el estómago a través de un pequeño orificio en el abdomen.

#### Conversaciones con el médico sobre la alimentación por sonda

Antes de explicar con detalle la alimentación por sonda, el médico le preguntará al paciente (o a sus seres queridos si el paciente no puede tomar una decisión por sí mismo) si está interesado en el procedimiento de alimentación por sonda. Algunas personas tienen una opinión muy clara sobre la alimentación por sonda y con frecuencia la comparten con sus seres queridos. El médico preguntará si el paciente ha realizado algún tipo de planificación anticipada de cuidados, si tiene un representante para cuidados médicos o si ha redactado un testamento vital. Asimismo, preguntará si el paciente ha hablado alguna vez con sus seres queridos acerca de sus preferencias de asistencia médica en ese tipo de situaciones. Determinar si se desea seguir una alimentación por sonda suele ser una decisión difícil.

Para tomar este tipo de decisión por un ser querido, es importante saber discernir qué es lo que el paciente querría si pudiera tomar dicha decisión por sí mismo, así como ser capaz de separar la voluntad del paciente de lo que uno desea para este. La decisión debería tomarse en función del deseo del paciente.

#### La decisión sobre la alimentación por sonda

A la hora de tomar una decisión sobre la alimentación por sonda, se han de tener muchos aspectos en cuenta. Es importante considerar las ventajas, desventajas y otras consideraciones en relación con la colocación de la sonda de alimentación. Asimismo, es importante analizar las ventajas, desventajas y otras consideraciones de continuar la alimentación por vía oral.

A la hora de tomar este tipo de decisión, uno puede hacerse las siguientes preguntas:

- ¿La vida de mi ser querido se alargará o se acortará como resultado de la colocación de una sonda de GEP?
- ¿Mejorará su calidad de vida? ¿Valoraría mi ser querido dicha calidad de vida?
- ¿Colocarle una sonda de GEP podría hacer posible la administración de un tratamiento que cure la enfermedad subyacente?

Por ejemplo, la alimentación por sonda dará resultados diferentes en una persona que ha sufrido un derrame cerebral pero que antes disfrutaba de una buena salud que en una persona que tiene la enfermedad de Alzheimer.

Las emociones suelen jugar un papel importante a la hora de decidir si se desea colocar una sonda de alimentación. Los sentimientos de culpa, como “no hacer todo lo que está en el poder de uno” para ayudar al paciente, y la presión de fuentes externas puede afectar al proceso de toma de decisiones. Por último, la opinión personal sobre la alimentación por sonda también influye en la decisión. Los representantes para cuidados médicos y los familiares deben tener en cuenta muchos aspectos antes de tomar una decisión sobre la alimentación por sonda. Las personas que optan por no seguir una alimentación por sonda pueden llevar una vida cómoda ingiriendo líquidos con pequeños sorbos y lubricándose la boca y los labios. La mayoría de los pacientes no sienten una mayor comodidad si se les coloca una sonda de alimentación. Existen algunas excepciones, como pacientes con lesiones graves que merman su capacidad para tragar y personas con cáncer incipiente de cabeza, cuello y esófago.

Si usted y sus familiares no se ponen de acuerdo en si al paciente se le debería colocar una sonda de alimentación o no, es importante pedir ayuda para tomar una decisión. El médico estaría dispuesto a reunirse con todos los miembros de la familia si de este modo pudiera ayudar en la toma de decisiones. Hablar con un capellán o guía religioso también puede resultar de ayuda.

#### El procedimiento de la alimentación por sonda

La colocación de una sonda de GEP suele llevar alrededor de quince minutos y comprende una serie de pasos. Se colocan alimentos líquidos en una bolsa y se introducen en el estómago a través de la sonda.

La alimentación por sonda puede realizarse durante un periodo de tiempo limitado. Una vez que se ha tomado la decisión de colocar la sonda de alimentación, también se puede decidir que se examine el uso de la sonda tras uno, dos o tres meses de su colocación para ver si sigue siendo la decisión correcta. Si se determina que no se están cumpliendo los objetivos originales de la alimentación por sonda, se puede tomar una nueva decisión para interrumpir el procedimiento.

#### Alternativas a la alimentación por sonda

Seguir realizando una alimentación por la boca (por vía oral) es una alternativa a la inserción de una sonda de GEP. La alimentación por vía oral también tiene sus ventajas y desventajas. Comer aporta placer al paciente al poder saborear los alimentos y mejora su interacción social con otras personas. Sin embargo, por lo general lleva más tiempo alimentar a personas que tienen dificultades para comer o tragar.

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

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

**GOALS FOR CARE**

| <b>DISEASES</b>  | <b>Prolongs Life</b>        | <b>Improves Quality of Life or Functional Ability<sup>3</sup></b> | <b>Enables a Cure or Reverses the Disease Process</b> |
|--|-----------------------------|---|---|
| Stroke<br>(good health in general before this)   | Likely                      | Up to 25% regain ability to swallow                               | Not Likely  |
| Stroke<br>(in poor health before this)   | Likely in the short term    | Not Likely  | Not Likely  |
|  | Not likely in the long term |   |   |
| Neurodegenerative Disease<br>[for example, Amyotrophic Lateral Sclerosis (ALS)] <sup>1</sup> | Likely                      | Uncertain   | Not Likely  |
| Persistent Vegetative State (PVS) <sup>2</sup>   | 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                  | Not Likely  | 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.

- 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. For patients associated with OPWDD a separate process must be followed, see OPWDD checklists.

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

### 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 funcional <sup>3</sup> | 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<br>Esclerosis Lateral<br>[por ejemplo, esclerosis lateral amiotrófica (EAL-ALS en inglés)] <sup>1</sup> | Probable                    | Incierto   | Poco probable  |
| Estado vegetativo persistente (EVP) <sup>2</sup>   | 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               | Poco probable  | 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

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

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