Monroe County Medical Society Community-wide Guidelines

Benefits/Burdens of Tube Feeding/PEG Placement for Adults

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

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

Benefits of PEG placement rather than feeding orally:

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

Burdens of PEG placement rather than feeding orally:

- 75% of stroke patients previously in good health not likely to have improved quality of life and/or functional status
- PVS patients not likely to have improved quality of life and/or functional status
- Possible patient agitation resulting in use of restraints
- Risk of aspiration pneumonia is the same or greater than that of patient being handfed
- Stroke patients previously in poor health, frail patients, and patients w/advanced dementia, cancer or organ failure have been reported to experience side effects: PEG site irritation or leaking (21%), diarrhea (22%), nausea (13%) and vomiting (20%)
- 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) A poor functional status means full or partial dependency in bathing, dressing, toileting, feeding, ambulation, or transfers.
2. Matched residents with and without a PEG insertion showed comparable sociodemographic characteristic, rates of feeding tube risk factors, and mortality. Adjusted for risk factors, hospitalized NH residents receiving a PEG tube were 2.27 times more likely to develop a new pressure ulcer (95% CI, 1.95-2.65). Conversely, those with a pressure ulcer were less likely to have the ulcer heal when they had a PEG tube inserted (OR 0.70 [95% CI, 0.55-0.89]). Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding Tubes and the Prevention or Healing of Pressure Ulcers. Archives of internal medicine. 2012;172(9):697-701. doi:10.1001/archinternmed.2012.1200.
3. Callahan CM, Haag KM, Weinberger M, et.al. Outcomes of Percutaneous Endoscopic Gastrostomy among Older Adults in a Community Setting. J Am Geriatr Soc. 2000 Sep; 48(9):1048-5
4. Sachdev, S., Refaat, T., Bacchus, I.D. et al. Age most significant predictor of requiring enteral feeding in head-and-neck cancer patients. Radiat Oncol 10, 93 (2015).
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.

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.

Approved Mar. 2022. Next scheduled review by Mar.2024

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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, 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.
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 is 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.
		If such a patient is in hospital or nursing home or hospice, 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: 1. A patient's authorized guardian 2. Spouse (if not legally separated) or domestic partner 3. Son or daughter over the age of 18 4. Parent 5. Brother/sister (age 18 or over) 6. Close friend (Must complete a signed statement as a close friend) Additionally, under this circumstance, two physicians or nurse practitioners or physician assistants must concur that either: 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 Special requirements exist for an Ethics Review Committee to determine that patient-centered and clinical standards are met: i. In a hospital, <u>other than a hospice</u>, if the attending physician or attending nurse practitioner or physician assistant* 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".
		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: 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
		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. 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."
	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.	**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.)