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| |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | 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 ulcers2. | 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 | *Likely* | *Likely in the short term* | *Likely* | *Likely* | Not Likely | Not Likely | Not Likely | Not Likely | | Not likely in the long term | | 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. 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](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555136/). 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

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 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,  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 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)   Additionally, under this circumstance, two physicians must concur that either:   * + 1. the patient has an illness or injury expected to cause death within six months, or     2. the patient is permanently unconscious, or     3. 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:   1. In a hospital, other than a hospice, if the attending physician disagrees with a decision to withhold or withdraw a feeding tube 2. 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 concur that:   1. life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND 2. 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 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 theMOLST 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.) |



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
* 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; anticholingerics: 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 (Consider “Comfort Oriented Feeding Only”):

* Offer and assist eating if needed but do not force food
* Patient preference and observed level of enjoyment 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](https://www.nysemolstregistry.com/Account/Login?ReturnUrl=%2f).

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
   1. clarify values and preferences
   2. explore prior experiences
   3. understand the meaning of the main approaches to the patient and family
   4. 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
4. medical knowledge about the patient’s disease process and prognosis
5. the ability of a feeding tube to alter the disease process and prognosis
6. the alternative approach to tube feeding
7. any knowledge of the patient’s past values if incapacitated
8. ASK – if there is information that needs more clarification, or if patient/family have questions about what they have heard
9. ASK - the patient and family should be asked what they think the best approach is given information above
10. if the clinician agrees, he or she should let it be known that they agree
11. if the clinician disagrees, he or she might ask them to say how they came to that conclusion
12. 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
13. the clinician should ask if they would like to hear what he or she recommends
14. 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
15. 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
16. differences of opinion should be respectfully and carefully negotiated looking for common ground
17. 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 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?

Tube Feeding/PEG Placement Guide

Patient Name  Date of Birth Date

Complete the blanks and check all that apply:

1. I have completed a global assessment and:

□ No reversible factors have been identified

□ Reversible factors have been identified and addressed, but eating/feeding/nutritional assessment have not

shown significant improvement

1. For this patient, the assessment of potential benefits of tube feeding are as follows (Refer to *Benefits and Burdens of PEG Placement* table, on page 1 of this guideline, as a method to complete this assessment):

□ Likely □ Uncertain □ Not Likely to prolong life

□ Likely □ Uncertain □ Not Likely to improve quality of life

□ Likely □ Uncertain □ Not Likely to enable potentially curative therapy or reverse the disease process

3. Discussions have taken place with:

Name of Medical Decision Maker

 Patient  Health Care Agent  Public Health Law Surrogate  § 1750-b Surrogate

Name(s) or other person(s) involved in the discussion

About:

□ understanding of current illness and prognosis (including functional recovery)

□ benefits and burdens of PEGs and other treatment options

□ patient’s advance directives, prior wishes, values, cultural & spiritual concerns, if any, and goals for care (rather than technical options)

4. □ Discussions about the above areas have been documented in the chart

1. Tube Feeding: □ WILLbe started □WILL NOTbe started
2. FOR PATIENTS WHO WILL START TUBE FEEDING:

* The tube feeding decision is based on:

□ prolonging life   
□ improving quality of life and/or functional status

□ enabling potentially curative therapy or reversing the disease process

□ other

Because the benefits or failures of tube feeding are likely to occur within 3-6 months following placement,

periodic reassessment is most important.

* The initial re-assessment of the need for tube feeding will be in: □ 30 days □ 60 days □ days #

Subsequent assessments will be based on clinical status.

* Need will be based on the following goals of therapy:

□ returning to baseline level of consciousness □ prolonging life

□ weight gain and/or improvement in nutrition □ improving quality of life and/or functional status

□ regaining ability to swallow □ enabling potentially curative therapy

□ other:

Physician (Designee) Signature Physician (Designee) Printed Name Date

Resources for Physicians

American Geriatrics Society

* [Position Statement](http://geriatricscareonline.org/ProductAbstract/american-geriatrics-society-feeding-tubes-in-advanced-dementia-position-statement/CL017) - Feeding Tubes in Advanced Dementia (2014)

[Choosing Wisely*®*](http://www.choosingwisely.org/)

*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](http://www.choosingwisely.org/about-us/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](http://www.choosingwisely.org/societies/american-academy-of-hospice-and-palliative-medicine/) and the [American Geriatric Society](http://www.choosingwisely.org/societies/american-geriatrics-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](http://www.choosingwisely.org/amda-releases-second-round-of-potentially-unnecessary-medical-tests-procedures-as-part-of-the-abim-foundations-choosing-wisely-campaign/) – 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: <http://geriatricresearch.medicine.dal.ca/clinical_frailty_scale.htm>

[CompassionAndSupport.org](http://www.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.

* [Feeding Tubes & Artificial Nutrition & Hydration](https://youtu.be/6fNcxIh5mxE) - addresses the benefits, burdens and challenges of artificial hydration/ nutrition and feeding tubes.
* [MOLST for Professionals](http://www.compassionandsupport.org/index.php/for_professionals/molst)

**OPWDD MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities** <https://opwdd.ny.gov/opwdd_resources/information_for_clinicians/documents/molst-checklist>

Professional Society Statements

Alzheimer’s Association. Feeding Tubes in Advanced Dementia. Approved 2015.alz.org/media/documents/feeding-issues-statement.pdf

American Gastroenterological Association. American Gastroenterological Association Medical Position Statement: Guidelines for the Use of Enteral Nutrition. Gastroenterology. 1995;108:1280-1301 **GASTROENTEROLOGY 1995-1301** <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](javascript:newshowcontent('active','authordisclosures');). 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/>

Resources for Patients

[ALS Association](http://www.alsa.org/als-care/resources/publications-videos/factsheets/feeding-tubes.html)

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

[Choosing Wisely*®*](http://www.choosingwisely.org/)

*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 patients’ 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](http://consumerhealthchoices.org/wp-content/uploads/2013/05/ChoosingWiselyFeedingTubeAGS-ER.pdf) version

[Spanish](http://consumerhealthchoices.org/wp-content/uploads/2013/05/ChoosingWiselyFeedingTubeAGS-ES.pdf) version

[CompassionAndSupport.org](http://www.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](https://youtu.be/6fNcxIh5mxE) - addresses the benefits, burdens & challenges of artificial hydration & nutrition and feeding tubes.
* [Patient and Family Stories](https://www.youtube.com/watch?v=OplXuGWMZKc) - describes decision regarding a feeding tube initially inconsistent with the patient's values)

[Health in Aging Foundation](http://www.healthinagingfoundation.org/haf_news/recommendations-on-the-use-of-feeding-tubes-in-people-with-advanced-dementia/) (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](http://decisionaid.ohri.ca/docs/das/Feeding_Options.pdf) - Decision aid that explains feeding options for people with dementia. (PowerPoint)
* [Helps educate families about feeding problems in people with dementia](https://vimeo.com/51776155) (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 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, is usually requires a longer period of time to feed someone who has problems eating or swallowing

Patient/Family/Clinician Information

Benefits and Burdens of Tube Feeding/PEG Placement

GOALS FOR CARE

|  |  |  |  |
| --- | --- | --- | --- |
| DISEASES | Prolongs Life | Improves Quality of Life or FunctionalAbility**3** | 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 | 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.

**Hoja inform**ativa para el paciente/familia/el clínico

Beneficios y dificultades del Alimentación por tubo/PEG

|  |  |  |  |
| --- | --- | --- | --- |
| 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 | Poco probable | Poco probable |
| Cáncer avanzado | Poco probable | Poco probable | Poco probable |

ETAS PARA EL CUIDADO

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

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