

# Tube Feeding/PEGs



## Purpose and Scope:

To provide data, information and tools to physicians, other clinicians and patients to help fully inform the decision making process around the use of tube feeding/PEG placement.

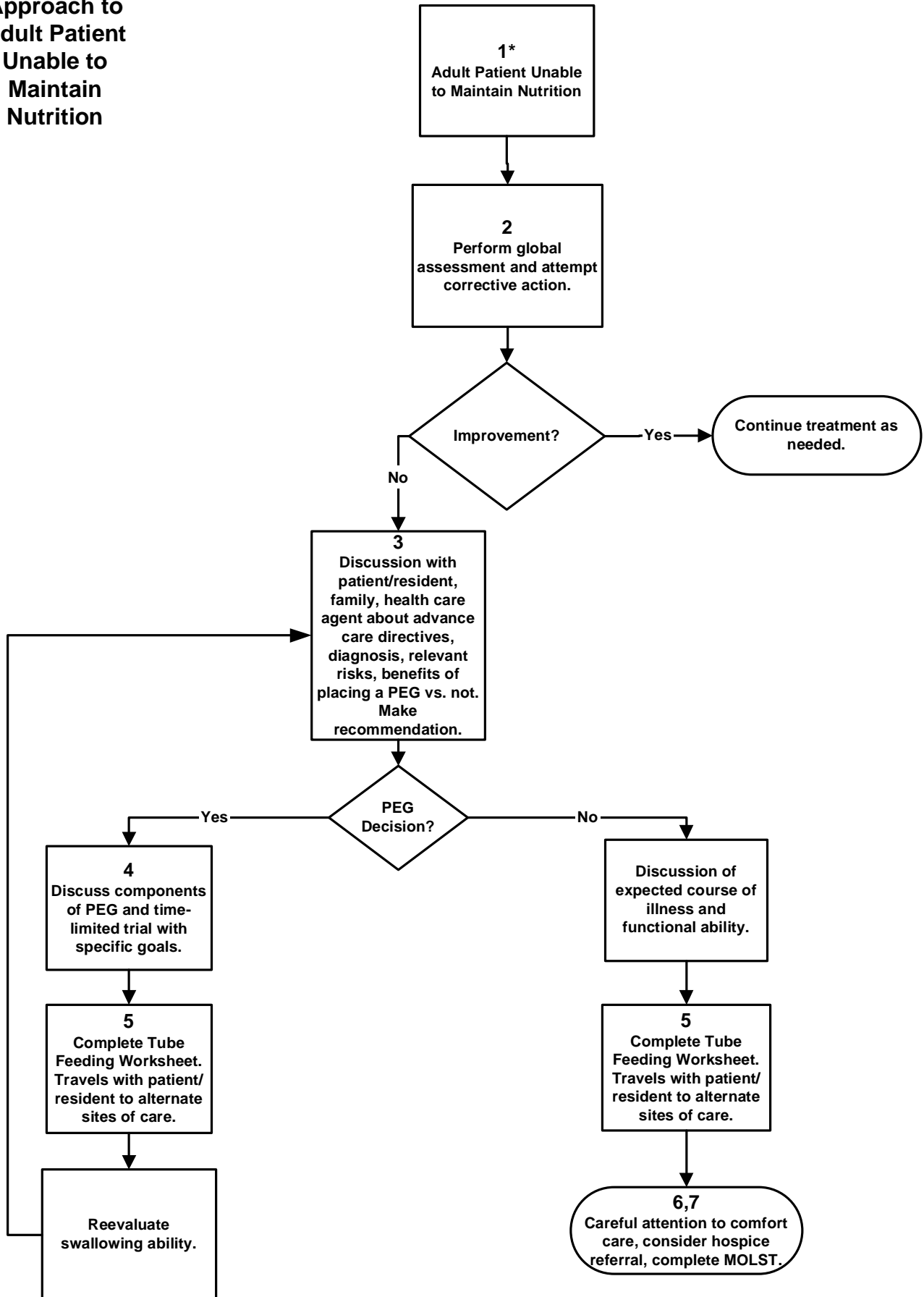
## Major Recommendations:

Prior to making a decision about PEG placement:

- Conduct a comprehensive assessment looking for reversible causes of inadequate nutrition
- Review the medical evidence as it relates to tube feeding/PEGs (see Goals of Care grid)
- Discuss the evidence with the patient, health care agent or family member
- Elicit family/patient understanding of present medical condition
- Discuss the benefits and burdens of tube feeding and whether this would be consistent with the patient's wishes

If tube feeding is elected, develop specific goals and time intervals for reviewing whether these goals have been achieved.

**Approach to  
Adult Patient  
Unable to  
Maintain  
Nutrition**



# Flow Chart Reference Sheet

## 1. Triggers for Assessment of Eating/Feeding/Nutrition:

- Weight loss
- Decreased eating (> 25 % left uneaten after most meals) NOTE: Clinicians often overestimate % eaten
- Pressure ulcers
- Presence of enteral or parenteral feedings
- Apparent aspiration and/or dysphagia following, or in the setting of acute illness

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

### ➤ Assess Parameters of Nutritional Status

- Weight change (1-2% or more in 1 week, 5% or more in one month, 7.5% or more in 3 months, 10% or > in 6 months)
- Account for possible fluid imbalance
- Body mass index of < 18.5 KG/meter squared
- Abnormal lab tests (albumin, pre-albumin, cholesterol, lymphocyte count)

### ➤ Identify Factors that Impede Ability to Take In Adequate Amounts of Food

- Physical limitations, visual problems
- Chewing problems (problems with mouth, teeth, dentures)
- Swallowing problems (feeding position, consistencies, bolus size, conducive environment, stimulus to swallow: verbal and tactile)
- Conditions that decrease nutrient intake (nausea, vomiting, constipation, cancer, shortness of breath, weakness)
- Alterations in taste secondary to medications, dry mouth, food options

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

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

### ➤ Perform Medical Assessment

- Stage of illness, prognosis, pain
- Assess for constipation/fecal impaction
- Adverse medication effects
  - Address the use of medications that can adversely affect either the ability to eat or the desire to do so. Classes of such drugs include those that induce dry mouth, decrease attentiveness, provoke movement disorders and/or cause GI distress of esophagitis.
  - Specific drugs might include:
    - ❖ sedatives: lorazepam; clonazepam, etc.
    - ❖ major tranquilizers: abilify, risperidone, 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/resident values, preferences, cultural and spiritual concerns
- general goals of 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**)

## 4. Discuss/Describe Components of PEG:

### ➤ Discuss Time-limited Trial with Specific Goals of Care

- return to baseline level of consciousness
- acceptable level of functioning
- nutritional bridge during an acute illness
- weight gain
- healing of pressure sores
- improved biochemical markers of nutrition

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

## 5. Tube Feeding Worksheet (Should be Completed for each Patient/Resident):

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

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

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

MOLST is a physician order form that helps health care providers honor the treatment wishes of their patients/residents. In some facilities, MOLST has replaced the DNR/DNI forms previously used. Page 2 of the MOLST form allows documentation of preferences about tube feeding. Use of one common, easily identifiable community-wide tool like MOLST (a bright pink form) leads to patients/residents receiving the care and treatment they prefer. To order MOLST forms, go to: [www.compassionandsupport.org/MOLST](http://www.compassionandsupport.org/MOLST).

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

\_\_\_\_\_  
Patient/Resident Name

\_\_\_\_\_  
Date of Birth

**Check each factor considered/addressed**

## Parameters of Nutritional Status

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

Comments about above factors: \_\_\_\_\_  
\_\_\_\_\_

## Factors that Impede Ability to Take in Food

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

Comments about above factors: \_\_\_\_\_  
\_\_\_\_\_

## Medical Assessment

- Stage of Illness : advanced or end stage illness
- ADL Score: current \_\_\_\_\_
- ADL Score: 1 month prior to admission \_\_\_\_\_
- Constipation/Fecal Impaction
- Other: \_\_\_\_\_

Comments about above factors: \_\_\_\_\_  
\_\_\_\_\_

## Potential Problem Medications

- Sedatives such as lorazepam; clonazepam
- Major Tranquilizers such as aripiprazole, risperidone
- Anticholinergics: tolterodine, oxybutynin chloride
- GI Irritants or Anorexigenics: NSAIDs, COX IIs, bisphosphonates, opioids, digoxin, theophylline, antibiotics, iron, calcium
- Cholinergics for Alzheimer's and other dementias: donepezil, galantamine, rivastigmine
- Other: \_\_\_\_\_

Comments about medications: \_\_\_\_\_  
\_\_\_\_\_

**Additional Comments:**

\_\_\_\_\_

\_\_\_\_\_

**Evaluating Clinician:** \_\_\_\_\_  
Name Initials Date

# Tube Feeding Worksheet

\_\_\_\_\_  
Patient/Resident Name

\_\_\_\_\_  
Date of Birth

\_\_\_\_\_  
Date

## **Complete the blanks and check all that apply:**

1. I have completed the eating/feeding/nutritional 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

2. For this patient/resident, the assessment of potential benefits of tube feeding are as follows:

- |                                 |                                    |                                     |  |
|---------------------------------|------------------------------------|-------------------------------------|--|
| <input type="checkbox"/> Likely | <input type="checkbox"/> Uncertain | <input type="checkbox"/> Not Likely | <b>to prolong life</b>   |
| <input type="checkbox"/> Likely | <input type="checkbox"/> Uncertain | <input type="checkbox"/> Not Likely | <b>to improve quality of life</b>  |
| <input type="checkbox"/> Likely | <input type="checkbox"/> Uncertain | <input type="checkbox"/> Not Likely | <b>to enable potentially curative therapy or reverse the disease process</b> |

3. Discussions have taken place with: \_\_\_\_\_

\_\_\_\_\_  
Name(s) of person(s)

### About:

- understanding of current illness and prognosis (including functional recovery)
- benefits and burdens of PEGs and other treatment options
- patient's/resident's advance directives, prior wishes, values, cultural & spiritual concerns, if any, and goals of care (rather than technical options)

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

5. Tube Feeding:  **WILL** be started  **WILL NOT** be started

6. **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 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
  - weight gain and/or improvement in nutrition
  - regaining ability to swallow
  - other: \_\_\_\_\_
  - prolonging life
  - improving quality of life and/or functional status
  - enabling potentially curative therapy

\_\_\_\_\_  
Physician (Designee) Signature

\_\_\_\_\_  
Physician (Designee) Printed Name

\_\_\_\_\_  
Date

## Benefits and Burdens of PEG Placement

	<b>Dysphagic Stroke</b>  (Patients with previous good quality of life, high functional status <sup>1</sup> and minimal co-morbidities)	<b>Dysphagic Stroke</b>  (Patients with decreased level of consciousness, multiple co-morbidities, poor functional status <sup>1</sup> prior to CVA)	<b>Amyotrophic Lateral Sclerosis (ALS) (Lou Gehrig' s Disease)</b>	<b>Persistent Vegetative State (PVS)</b>	<b>General Frailty</b>  (Patients with multiple co-morbidities, poor functional status, failure to thrive)	<b>Advanced Dementia</b>  (Patients needing help with daily care, having trouble communicating, and/or incontinent)	<b>Advanced Cancer</b>  (Excludes patients with early stage esophageal & oral cancer)	<b>Advanced Organ Failure</b>  (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>  <i>Not likely in the long term</i>	<i>Likely</i>	<i>Likely</i>	Not Likely	Not Likely <sup>2</sup>	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

### 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 poor health previously, 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 associated 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%)<sup>3</sup>

### 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. A poor functional status means full or partial dependency in bathing, dressing, toileting, feeding, ambulation, or transfers.

2. There is a small group of patients who fall into this category whose life could be prolonged.

3. Callahan CM, Haag KM, Weinberger M, Tierney WM, Buchanan NN, Stump TE, Nisi R. Outcomes of Percutaneous Endoscopic Gastrostomy among Older Adults in a Community Setting." *J Am Geriatr Soc.* 2000 Sep; 48(9):1048-54.

## Legal and Ethical Issues Related to PEGS/Tube Feeding

### For patients/residents who CAN make decisions for themselves:

**The usual standards of informed consent (or refusal) apply.** 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/resident 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).

### For patients/residents who CANNOT make decisions for themselves:

**If the patient/resident has completed a health care proxy form** 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).

**If the patient/resident has not completed a health care proxy form,** the legal standard for withholding or withdrawing a feeding tube is currently different depending upon whether the patient/resident resides in a medical facility (hospital or nursing home) or elsewhere (residential home).

- **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/resident’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 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, if the attending physician disagrees with a decision to withhold or withdraw a feeding tube;
- ii. In a nursing home, for all life-sustaining treatment, including a feeding tube.

- **If the 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:**
  - 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 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.”

# Legal and Ethical Issues Related to PEGS/Tube Feeding

## In discussions with patients/residents and families:

### FOCUS ON THE PATIENT'S OWN VALUES, PREFERENCES AND BELIEFS:

- Focus on the underlying disease process as cause of decline and loss of appetite
- Emphasize the active nature of providing comfort care
- Recognize the concerns about “starvation”, inadequate nutrition or hydration and potentially hastening death that many individuals deal with in facing this decision and address these issues
- Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food and drink. Health care facilities are required to offer nutrition and hydration orally, without reliance on medical treatment, to inpatients/residents who are able to eat or drink.

### UNDERSTAND CULTURAL AND RELIGIOUS VALUES:

- Most cultures and religions recognize death as a normal aspect of life. Most allow for weighing the benefits and burdens of medical treatment including tube feeding
- Explore religious and cultural values that might influence the decision about tube feeding
- When in doubt or unfamiliar about a patient's/resident's belief system, consult with a chaplain or spiritual leader from their own tradition if possible
- Recognize there is variation within a culture. It is best to ask the patient's decision-maker about the patient's values and beliefs.
- Recognize how one's own religious or spiritual feelings affect how tube feeding is discussed with patients/residents and their families, and attempt to minimize the influence these factors might have on the decision-making process.

**BENEFITS AND BURDENS OF PEGS/TUBE FEEDING  
PATIENT/FAMILY INFORMATION SHEET**

**GOALS OF CARE**

<b>DISEASES</b>	<b>Prolongs Life</b>	<b>Improves Quality of Life or Functional<sup>3</sup> Ability</b>	<b>Enables a Cure or Reverses the Disease Process</b>
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		
ALS Lou Gehrig's Disease <sup>1</sup>	Likely	Uncertain	Not Likely
Persistent Vegetative State <sup>2</sup>	Likely	Not Likely	Not Likely
Advanced Organ Failure	Not Likely	Not Likely	Not Likely
General Frailty	Not Likely	Not Likely	Not Likely
Advanced Dementia	Not Likely <sup>4</sup>	Not Likely <sup>4</sup>	Not Likely
Advanced Cancer	Not Likely	Not Likely	Not Likely

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

1. A severe disease affecting the brain and spinal cord.

2. Person with severe brain damage with no awareness.

3. Ability to do things like eating, dressing, going to the bathroom without assistance.

4. There is a small group of patients who fall into this category whose life could be extended.

## BENEFITS AND BURDENS OF PEGS/TUBE FEEDING PATIENT/FAMILY INFORMATION SHEET

### Benefits of having a feeding tube (PEG) rather than feeding by mouth:

- Family members/caregivers avoid guilt and conflict associated with choosing other treatment options
- Family members/caregivers given additional time to adjust to possibility of impending death
- Family members/caregivers can maintain hope for future improvement

### Burdens of having a PEG rather than feeding by mouth:

- PEG patients may become restless and need to be restrained
- Patients with PEG tubes may have the following symptoms, some of which may be caused by the tube (diarrhea, vomiting) and some made worse by the tube (skin breakdown from diarrhea, lung congestion, aspiration pneumonia)

### Benefits of feeding by mouth rather than through a feeding tube (PEG):

- Patient able to enjoy taste of food
- Patient has greater opportunity for social interaction
- Patient's wishes and circumstances taken into account in terms of pace, timing and volume of feeding

### Burdens of feeding by mouth rather than having a PEG:

- Feeding a patient by mouth requires a longer period of time
- Patient/family worry about "not doing everything in their power" to address the feeding problems" and/or "starving the patient"
- For certain stroke, ALS, and PVS patients, family/caregivers feel in not choosing an option that can extend life, they are hastening death

*Risk of getting aspiration pneumonia, pneumonia due to having saliva or food go into your lungs when breathing, is same or greater for the PEG patient than the handfed patient.*

# Questions to Consider When Making A Decision About PEGs/Tube Feeding\*

## What is your family member's situation?

- is the underlying condition causing the eating problem likely to get better?
- is the feeding tube needed to help provide nutrition?
- how concerned are you about specific complications of the feeding tube (such as minor or major tube problems, bleeding, infections)?
- is the patient likely to become agitated with the tube and need to be restrained to keep it in?
- will feeding tube placement make a difference as to where the patient can live?
- is the patient aspirating, inhaling material into his/her lungs?
- does the patient have any of the factors associated with decreased chances of survival?
- how will the feeding tube affect the person's quality of life?

## What would your family member want?

- has s/he ever expressed her wishes (in a living will or previous discussion) about the use of medical technologies like feeding tubes?
- what are his/her beliefs and values about end-of-life care?
- if s/he could weigh the advantages and disadvantages, what do you think s/he would choose?
- what do you feel is in your family member's best interests?

## How the decision is affecting you:

- are you having feelings of guilt?
- are you feeling pressure from others?
- is there any conflict between your personal beliefs and those of the patient?
- do you worry about the future decisions regarding continuing with the tube?

## What questions need answering before you can decide?

## Who should decide about placing the tube?

## What is my overall "leaning" about placing a feeding tube?

\*Excerpted from Making Choices: Long Term Feeding Tube Placement in Elderly Patients by Mitchell, Tetroe and O'Connor

## **To Help You Make A Decision About Tube Feeding<sup>1</sup>**

Before they are seriously ill or approaching death, some individuals have completed a health care proxy and living will, and discussed their wishes at great length with a health care spokesperson. In these cases, the health care spokesperson may have a clear understanding of the person's preferences regarding tube feeding. However, in many cases the patient or the health care spokesperson is unclear about what choice to make. At that point, all of the benefits and burdens of tube feeding over eating or drinking by mouth need to be considered so an informed decision can be made.

### **Eating At the End of Life**

In all cultures and throughout all history, offering food has been a sign of caring and hospitality. Our mothers made sure we were well fed. Most people enjoy eating with family and friends, especially on special occasions. In most religions, food is part of sacred rituals. It is no wonder, then, when someone we love is unable to eat and drink naturally, that we feel compelled to "feed" them in some way. It seems to be basic caring.

But, as death approaches, you will not "keep up your strength" by forcing yourself to eat when it makes you uncomfortable. If eating is a social event for you, or providing food is one of the common ways of expressing caring in your family, your loss of appetite may be distressing to you and your loved ones. You might enjoy small amounts of home-cooked food, dishes that mean something special to you. However, you should also know that a decrease in appetite is natural and eating less may increase, rather than decrease, comfort.

Because most dying people are more comfortable without eating or drinking near the end of life, giving food or liquids to them by tube feeding is usually not beneficial, especially if restraints (a tool that limits movement), IVs (used to supply fluids into your veins), or hospitalization are required.

The truth is, for those who are dying, the time comes when it might be more compassionate, caring, even natural, to allow a natural dehydration (loss of body water) to occur. Tube feeding and providing fluid through an IV can make the last days of their lives more uncomfortable.

### **Tube Feeding for the Stroke Patient**

Sometimes people who suffer a stroke cannot swallow at first and a tube is inserted to provide nutrition (food) and hydration (liquid). Sometimes these patients can learn to eat again, and the tube is eventually removed. Sometimes a patient with throat cancer might not be able to swallow after successful treatment of the disease. He or she may have a feeding tube and still carry on otherwise normal activities. Few would question whether feeding tubes are appropriate in cases like these. But there are cases where feeding tubes and IVs are more of a burden to the patient than a benefit.

## **A Trial of Tube Feeding**

Tube feeding, taking in food and liquids artificially, can be done for a period of time and then stopped.

If death is not expected in hours to days, you and your family may consider a time-limited trial of artificial food or liquid to see if it improves comfort, alertness, or energy. To give tube feedings for a short period of time, a tube is usually threaded through the nose into the stomach. For longer periods of tube feedings, tubes (called PEGs) may be placed through the abdomen directly into the stomach. A PEG tube may be placed in a patient by a gastroenterologist (stomach doctor) or surgeon, depending on the patient's other medical problems. Intravenous (IV) catheters, a different type of a thin hollow tube, are usually placed in the veins of the arm or hand to provide liquids. If IVs are going to be used for food as well as liquids, then larger IVs usually must be placed in the large veins of the arm, neck, chest, or groin (area where the thigh meets the hip).

You and your family should agree in advance with your doctor about what you hope to accomplish from being provided with artificial food or liquids. You should also determine, in advance, how long to wait to see if you are getting any better before removing the tubes.

The evidence from medical research and patients' bedsides suggests that it is often more comfortable to die without artificial liquids provided either by a feeding tube or into the veins. Until this generation, everyone who died a natural death died without artificially supplied fluids. Refusing food and drink has always been a sign of the last phase of serious condition leading to death. Only recently have people been afraid that not providing food and fluid through a tube would force someone to "starve to death." There is no medical or clinical evidence that not putting a feeding tube or IV into a person leads to a more painful death. In fact, the research says just the opposite.<sup>2</sup>

Without artificial liquids there tends to occur a loss of body water resulting in a dry mouth. Very few people feel any thirst. Dry mouth can be easily addressed with good mouth care, ice chips or a moistened sponge swab.

## **Tube Feeding and the Dementia Patient**

Increased difficulty with eating and swallowing is one of the signs that an Alzheimer's patient has moved into the final stages of the disease. An Alzheimer's patient may tend to choke on food and drink, running the risk of an infection affecting one's breathing. This person may lose interest in food or forget how to swallow. These signs mark the end of a very sad and long disease process. By this point the patient is often totally dependent on others for care, unable to go back and forth to the

bathroom or use a bed pan, unable to recognize family or to speak in a manner that makes sense.

Some may choose to treat the reduction in food and fluid intake with a feeding tube. Family, doctors, or nurses may say they do not want the patient to "starve" to death. Providing tube feeding is certainly an acceptable way to provide care.

However, the patient isn't feeling any hunger. The inability to eat is an expected part of the final stage of a person's life. Inserting a tube will not stop the progression of a fatal disease, though it might affect the length of time it takes for a person to go through the last stages of dying. Since dying without fluid intake is comfortable, many loved ones choose to forgo the tube feeding. Offer the patient whatever he or she can tolerate by spoon feeding and drinking. Sips of water and ice chips can relieve dry mouth. This decision poses the kind of perplexing situation that may become clearer as society has more experience with it.

### **Tube Feeding When the Person is Unconscious**

Many people can be supported with artificial feeding even though they do not seem to be conscious or aware. Some stroke patients may never again respond to what is happening around them. Many young people have suffered a head injury and are also permanently unconscious. Two well-known court cases involved Karen Ann Quinlan and Nancy Cruzan, who both lived for years supported by feeding tubes, though they were never aware of their surroundings. These patients are said to be in a **persistent vegetative state**. Are we obligated to keep such patients alive even though there is no hope of their recovery to a state of awareness? If we do choose to withdraw the tube feeding, would these patients experience a painful death? Would we be killing the patient?

The courts and medical practice have ruled it acceptable to withhold or withdraw tube feedings from such patients. Many faith communities have weighed in on decisions like these as well. The real struggle for the families of these patients is an emotional and spiritual one. If the patient could make his or her own decision, would the choice be to start tube-feeding or not, or to try it on a time-limited basis? What role does the patient's faith play in this decision? Are we making decisions that honor the patient's wishes or *our wishes for the patient*?

1. 1152w from "Handbook for Mortals: Guidance for People Facing Serious Illness"  
By Joanne Lynn, MD and Joan Harrold, MD (2001). Free permission. Author's own material.  
By permission of Oxford University Press, Inc.

2. McCann RM, Hall WJ, Groth-Juncker A. "Comfort Care for Terminally Ill Patients:  
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## References for PEGs/Tube Feeding Guidelines

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# Información para el paciente sobre los beneficios y dificultades del PEG

## METAS DEL CUIDADO

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	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	Hasta el 25% posibilidad de recuperar la habilidad de tragar	Poco probable
Derrame cerebral (salud pobre antes de esto)	Probable a corto plazo	Poco probable	Poco probable
	Poco probable a largo plazo		
ELA Enfermedad de Lou Gehrig <sup>1</sup>	Probable	Incierto	Poco probable
Estado vegetativo persistente <sup>2</sup>	Probable	Poco probable	Poco probable
Insuficiencia de órganos avanzada	Poco probable	Poco probable	Poco probable
Debilidad general	Poco probable	Poco probable	Poco probable
Demencia avanzada	Poco probable <sup>4</sup>	Poco probable	Poco probable
Cáncer avanzado	Poco probable	Poco probable	Poco probable

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

1. Una enfermedad grave que afecta el cerebro o la médula espinal

2. Persona con daño cerebral grave sin conciencia

3. Habilidad de hacer cosas tales como comer, vestirse, ir al baño sin asistencia

4. Hay un pequeño grupo de pacientes que caen en esta categoría cuya vida puede ser extendida

**Beneficios de tener un tubo gástrico (PEG) en lugar de alimentar por boca:**

- Familiares/proveedores de cuidado evitan la culpa y conflicto asociados con la elección de otras opciones de tratamiento
- Familiares/proveedores de cuidado tienen tiempo adicional para prepararse a la posibilidad de una muerte inminente
- Familiares/proveedores de cuidado pueden mantener la esperanza en mejoras futuras

**Dificultades de tener un PEG en lugar de alimentar por boca:**

- Los pacientes con PEG pueden ponerse impacientes y es necesario restringirlos
- Pacientes con tubos PEG pueden sufrir los síntomas siguientes, algunos de los cuales pueden ser causados por el tubo (diarrea, vómito) y algunos empeorar-se debido al tubo (lesión de la piel debido a la diarrea, congestión pulmonar, neumonía por aspiración)

**Beneficios de alimentar por boca en lugar de a través de un tubo gástrico (PEG):**

- El paciente puede disfrutar del sabor de la comida
- El paciente tiene mayor oportunidad para la interacción social
- Se toman en consideración los deseos y circunstancias del paciente en términos de ritmo, regulación y volumen de alimentos

**Dificultades de alimentar por boca en lugar de tener un PEG:**

- Alimentar al paciente por boca requiere más tiempo
- Paciente/familia preocupados por “no estar haciendo todo lo posible en su poder” para resolver los problemas de alimentación ” y/o “estar matando de hambre al paciente”
- Para ciertos pacientes que sufrieron un derrame cerebral, ELA o EVP, la familia/proveedores de cuidado sienten que al no elegir una opción que pueda extender la vida, están apresurando la muerte

*El riesgo de tener neumonía por aspiración, neumonía debida a la existencia de saliva o alimentos en sus pulmones cuando respira, es el mismo o mayor para el paciente con PEG que para el paciente que debe ser alimentado.*

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

## **Para ayudarle a tomar una decisión sobre el tubo gástrico<sup>1</sup>**

Antes de estar seriamente enfermos o acercándose a la muerte, algunos individuos completan un poder (proxy) médico y testamento vital, y discuten sus deseos en detalle con el portavoz del cuidado médico. En esos casos, el portavoz del cuidado médico conoce claramente las preferencias de la persona con respecto al tubo gástrico. Sin embargo, en muchos casos el paciente o el portavoz del cuidado médico no tienen claro qué elección deben hacer. En ese momento, se deben considerar todos los beneficios y dificultades necesarios del tubo de alimentación en lugar de la comida y bebida por boca para poder tomar una decisión informada.

### **Alimentación al final de la vida**

En todas las culturas y a través de toda la historia, ofrecer alimentos siempre ha sido un signo de afecto y hospitalidad. Nuestras madres se aseguraban de que estuviésemos bien alimentados. La mayoría de las personas disfrutan comiendo con familiares y amigos, principalmente en ocasiones especiales. En la mayoría de las religiones, la comida es parte de rituales sagrados. No es una sorpresa, entonces, que cuando un ser querido no puede comer ni beber naturalmente, sintamos la obligación de "alimentarlo" de alguna manera. Parece como la atención básica.

Pero, cuando la muerte se acerca, usted no "mantendrá su fortaleza" obligándose a comer si eso lo hace sentirse mal. Si para usted comer es un evento social, o si proporcionar alimentos es una de las formas comunes en que su familia expresa su afecto, la pérdida de apetito es posiblemente perturbadora para usted y para sus seres queridos. Es posible que pueda disfrutar de pequeñas cantidades de comida casera, platos que tienen un significado especial para usted. Pero, debe saber que la disminución de apetito es natural y comer menos lo hace sentir más cómodo, en lugar de lo contrario.

Debido a que la mayoría de las personas que se están muriendo se sienten más cómodas sin comer ni beber al acercarse el final de la vida, darle comida o líquidos por un tubo gástrico no es muy beneficioso, especialmente si hay que forzarlo con sujeciones (un instrumento que limita el movimiento), IV (usadas para suministrar líquidos en las venas) u hospitalización.

La verdad es, que estando cerca de la muerte, llega un punto en que es más compasivo, solidario, incluso más natural, permitir la deshidratación natural (pérdida del agua del cuerpo). Un tubo gástrico y suministrar líquido por vía intravenosa (IV) puede hacer los últimos días de sus vidas más incómodos.

### **Tubo gástrico para el paciente de un derrame cerebral**

A veces las personas que han sufrido un derrame cerebral al principio no pueden tragar y se les inserta un tubo para poder alimentarlos (alimentos) e hidratarlos (líquido). A veces estos pacientes pueden aprender a comer nuevamente, y el tubo eventualmente se retira. A veces un paciente con cáncer de garganta no puede tragar después de un tratamiento exitoso de la enfermedad. Él puede tener un tubo gástrico y ser capaz aún así de realizar actividades normales. Muy pocos cuestionarán si los tubos gástricos son adecuados en esos casos. Pero hay casos en los que los tubos gástricos y las IV son más una dificultad para el paciente que un beneficio.

## **Un período de prueba de la alimentación por tubo**

La alimentación por un tubo, que consiste en tomar alimentos y líquidos artificialmente, se puede hacer por un período de tiempo y luego interrumpir.

Si la muerte no se espera en horas o días, usted y su familia deben considerar un período de prueba limitado de alimento o líquido artificial para ver si mejora la comodidad, estado de alerta o energía. Cuando se trata de un tubo de alimentación por un corto período de tiempo, generalmente se inserta el tubo a través de la nariz al estómago. Para períodos más largos, se usan tubos (llamados PEG) que se colocan a través del abdomen directamente al estómago. Un tubo PEG puede colocarlo en el paciente un gastroenterólogo (médico especialista del estómago) o un cirujano, dependiendo de los otros problemas médicos del paciente. Los catéteres intravenosos (IV), un tipo diferente de tubo hueco fino, se colocan generalmente en las venas del brazo o la mano para suministrar líquidos. Si se van a usar IV tanto para alimentos como para líquidos, se deben colocar IV más grandes en venas más grandes del brazo, cuello, pecho o ingle (área donde el muslo se une a la cadera).

Usted y su familia deben estar de acuerdo con su médico de antemano sobre lo que desea lograr cuando le proporcionan alimentos o líquidos artificiales. También debe determinar, por anticipado, cuánto tiempo esperar para ver si está mejorando antes de retirar los tubos.

La evidencia basada en la investigación médica y experiencias de los pacientes indica que es a menudo más cómodo morir sin líquidos artificiales provistos ya sea con un tubo gástrico o por las venas. Hasta esta generación, las personas morían de muerte natural sin líquidos suministrados artificialmente. Negarse a comer y beber ha sido siempre un signo de la última fase de una condición seria que conduce a la muerte. Sólo recientemente las personas comenzaron a temer que no proveer alimento y líquido por un tubo hace que el paciente "se muera de hambre". No existe evidencia médica ni clínica de que por no colocar un tubo gástrico o IV en una persona, su muerte será más dolorosa. De hecho, la investigación dice todo lo contrario.<sup>2</sup>

Sin líquidos artificiales tiende a perderse el agua del cuerpo y eso produce sequedad en la boca. Muy pocas personas sienten sed. La sequedad de la boca se puede aliviar fácilmente con el cuidado de la boca, trozos de hielo o un hisopo de esponja húmedo.

## **Tubo de alimentación y el paciente con demencia**

El aumento de la dificultad para comer y tragar es uno de los signos de que un paciente con Alzheimer ha entrado en las fases finales de la enfermedad. Un paciente con Alzheimer puede atragantarse con comida o bebida, corriendo el riesgo de una infección que le afecte la respiración. Esa persona puede perder el interés en la comida u olvidarse de cómo tragar. Esos signos marcan el final del proceso de una enfermedad muy triste y prolongada. A esta altura, el paciente con frecuencia depende completamente del cuidado de otros, es incapaz de ir al baño

o usar un bacín, incapaz de reconocer a su familia o de hablar de forma que tenga sentido.

Algunas personas elegirán el uso de un tubo gástrico para tratar la reducción de alimento y líquido. La familia, médicos o enfermeras dirán que no quieren que el paciente se "muera de hambre". El uso del tubo de alimentación es indiscutiblemente una forma aceptable de proporcionar cuidado.

Sin embargo, el paciente no siente hambre. La imposibilidad de comer es un hecho anticipado en las etapas finales de la vida de una persona. La inserción de un tubo no interrumpirá la evolución de una enfermedad fatal, si bien puede afectar la duración del tiempo que llevará a la persona alcanzar su muerte. Debido a que morir sin tomar líquido es más cómodo, muchos seres queridos eligen no usar el tubo de alimentación. Pueden ofrecerle al paciente lo que es capaz de tolerar comiendo o bebiendo con una cuchara. Sorbos de agua y trozos de hielo pueden aliviar la sequedad de la boca. Esa decisión plantea la clase de situación desconcertante que se irá aclarando cuando la sociedad tenga mayor experiencia con ello.

### **Alimentación por tubo cuando la persona está inconsciente**

A muchas personas se las puede mantener con alimentación artificial incluso si no están conscientes o no entienden lo que sucede. Algunos pacientes con derrame cerebral nunca más responden a lo que sucede a su alrededor. Muchos jóvenes han sufrido una lesión en la cabeza y están también permanentemente inconscientes. Dos casos que fueron a la corte y son muy conocidos son los de Karen Ann Quinlan y Nancy Cruzan, ambas vivieron por años alimentadas con tubos, y nunca pudieron tener conciencia de su alrededor. Esos pacientes se dice que están en un **estado vegetativo persistente**. ¿Debemos mantener a esos pacientes vivos a pesar de que no hay esperanza de que recuperen un estado de conciencia? ¿Si decidimos sacar el tubo de alimentación, experimentarán esos pacientes una muerte dolorosa? ¿Estaremos matando al paciente?

Las cortes y la práctica médica han dictaminado que es aceptable no colocar los tubos de alimentación o retirarlos de esos pacientes. Muchas comunidades religiosas están también pesando estas decisiones. El conflicto real para las familias de estos pacientes es de carácter emocional y espiritual. ¿Si el paciente pudiese tomar su propia decisión, que haría, comenzaría con un tubo de alimentación o no, o lo intentaría por un tiempo limitado? ¿Qué rol juega la fe del paciente en esa decisión? ¿Estamos tomando decisiones que respetan los deseos del paciente o *son nuestros deseos para el paciente*?

1. Adaptado del Handbook for Mortals: Guidance for People Facing Serious Illness Joanne Lynn, MD y Joan Harrold, MD: 1999 Oxford University Press.  
2. McCann RM, Hall WJ, Groth-Juncker A. "Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration." Journal of the American Medical Association 1994; 272 (16): 1263-1266.

# Preguntas que merecen ser consideradas cuando se toma una decisión sobre PEG/tubo gástrico\*

## ¿Cuál es la situación de su familiar?

- ¿es posible que mejore la condición subyacente que causa el problema de alimentación?
- ¿es el tubo gástrico necesario para ayudar a proveer nutrición?
- ¿cuán preocupado está usted acerca de las complicaciones específicas del tubo gástrico (tales como problemas menores o mayores del tubo, pérdida de sangre, infecciones)?
- ¿es posible que el paciente se agite con el tubo y sea necesario tomar medidas para mantenerlo colocado?
- ¿hará la colocación del tubo gástrico alguna diferencia respecto al lugar donde pueda vivir el paciente?
- ¿está el paciente aspirando, inhalando material a sus pulmones?
- ¿tiene el paciente alguno de los factores asociados con pocas probabilidades de supervivencia?
- ¿de qué manera el tubo gástrico afectará la calidad de vida de la persona?

## ¿Qué querría su familiar?

- ¿ha él/ella expresado alguna vez sus deseos (en un testamento vital o discusión previa) acerca del uso de tecnologías médicas como los tubos gástricos?
- ¿cuáles son sus creencias y valores sobre el cuidado al final de la vida?
- ¿si él/ella pudiese evaluar las ventajas y desventajas, qué piensa usted que elegiría?
- ¿qué piensa usted que es lo mejor para su familiar?

## De qué forma le afecta a usted la decisión:

- ¿tiene sentimientos de culpa?
- ¿siente la presión de otros?
- ¿existe algún conflicto entre sus creencias personales y las del paciente?
- ¿le preocupan las decisiones futuras relacionadas con la continuación del tubo?

## ¿Qué respuestas necesita antes de poder decidir?

## ¿Quién debe decidir sobre la colocación del tubo?

## ¿Cuál es mi “tendencia” general sobre la colocación de un tubo gástrico?

\*Extraído de Making Choices: Long Term Feeding Tube Placement in Elderly Patients de Mitchell, Tetroe y O'Connor