Tube Feeding/PEG Placement for Adults

Resources for Patients

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

Choosing Wisely®
Choosing Wisely® is an initiative of the American Board of Internal Medicine Foundation to help physicians and patients engage in conversations to help make wise decisions about the most appropriate care based on a 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 version](#)
  - [Spanish version](#)

CompassionAndSupport.org
Educates and empowers patients, families and professionals on issues related to advance care planning, health care proxies, MOLST, palliative care, and pain management). Videos available:
- Discussing Feeding Tubes & Artificial Nutrition & Hydration - addresses the benefits, burdens & challenges of artificial hydration & nutrition and feeding tubes.
- Patient and Family Stories - describes decision regarding a feeding tube initially inconsistent with the patient's values

Health in Aging Foundation (Foundation of the American Geriatric Society)
Recommendations on the use of feeding tubes in people with advanced dementia.

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

University of North Carolina Palliative Care Program
- Making Choices: Feeding Options for Patients with Dementia - Decision aid that explains feeding options for people with dementia. (PowerPoint)
- Helps educate families about feeding problems in people with dementia (video)
Patient/Family/Clinician Information  
To Help You Make a Decision About Tube Feeding/PEG Placement

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

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

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

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

The questions you might ask in regards to this decision are:
Will my loved one live longer, or possibly die sooner, as a result of having a PEG tube placed?
Will the quality of their life improve and will that quality of life be something they would value?
Will placing a PEG allow for treatment that is likely to cure their underlying illness?

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

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

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

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

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

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

<table>
<thead>
<tr>
<th>DISEASES</th>
<th>Prolongs Life</th>
<th>Improves Quality of Life or Functional Ability</th>
<th>Enables a Cure or Reverses the Disease Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke (good health in general before this)</td>
<td>Likely</td>
<td>Up to 25% regain ability to swallow</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Stroke (in poor health before this)</td>
<td>Likely in the short term</td>
<td>Not Likely</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Not likely in the long term</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurodegenerative Disease [for example, Amyotrophic Lateral Sclerosis (ALS)]</td>
<td>Likely</td>
<td>Uncertain</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Persistent Vegetative State (PVS)</td>
<td>Likely</td>
<td>Not Likely</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Advanced Organ Failure</td>
<td>Not Likely</td>
<td>Not Likely</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Frailty</td>
<td>Not Likely</td>
<td>Not Likely</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Advanced Dementia</td>
<td>Not Likely⁴</td>
<td>Not Likely⁴</td>
<td>Not Likely</td>
</tr>
<tr>
<td>Advanced Cancer</td>
<td>Not Likely</td>
<td>Not Likely</td>
<td>Not Likely</td>
</tr>
</tbody>
</table>

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.

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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.

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

ETAS PARA EL CUIDADO

<table>
<thead>
<tr>
<th>ENFERMEDADES</th>
<th>Prolonga la vida</th>
<th>Mejora la calidad de vida o habilidad funcional&lt;sup&gt;3&lt;/sup&gt;</th>
<th>Permite la cura o revierte el proceso de la enfermedad</th>
</tr>
</thead>
<tbody>
<tr>
<td>Derrame cerebral (buena salud en general antes de esto)</td>
<td>Probable</td>
<td>Posibilidad de recuperar la habilidad de tragar de hasta 25%</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Derrame cerebral (salud pobre antes de esto)</td>
<td>Probable a corto plazo</td>
<td></td>
<td>Poco probable</td>
</tr>
<tr>
<td></td>
<td>Poco probable a largo plazo</td>
<td></td>
<td>Poco probable</td>
</tr>
<tr>
<td>Neurodegenerativas</td>
<td>Probable</td>
<td>Incierto</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Esclerosis Lateral</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[por ejemplo, esclerosis lateral amiotrófica (EAL-ALS en inglés)]&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Estado vegetativo persistente (EVP)&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Probable</td>
<td>Poco probable</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Fallo avanzado de los órganos</td>
<td>Poco probable</td>
<td>Poco probable</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Debilidad</td>
<td>Poco probable</td>
<td>Poco probable</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Demencia avanzada</td>
<td>Poco probable&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Poco probable&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Poco probable</td>
</tr>
<tr>
<td>Cáncer avanzado</td>
<td>Poco probable</td>
<td>Poco probable</td>
<td>Poco probable</td>
</tr>
</tbody>
</table>

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

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

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