



Tube Feeding

"I've been asked to decide about a feeding tube..."

Making a decision about a long-term feeding tube for yourself or for someone you love may be challenging and emotional. Those who have faced a similar decision have told us that having honest answers to their questions was most helpful.

HOWEVER.....Every situation is different... what may help someone with a short term correctable eating problem may not be best for long-term use for a person who is in the final stages of a terminal illness.

COALITION *for* COMPASSIONATE CARE *of* CALIFORNIA

What is a feeding tube?

A temporary feeding tube can be inserted through the nose into the stomach (N-G tube) for short term use. A feeding tube for long term use is called a Percutaneous Endoscopic Gastrostomy (PEG) tube. A small surgical opening is cut through the skin and stomach to place the tube that allows formula to be delivered directly to the stomach.

Who is helped most by having a feeding tube?

Those who function independently but are receiving chemotherapy or radiation for certain cancers and some stroke survivors in rehabilitation whose swallowing ability is expected to return may benefit from temporary feeding tubes. Persons with ALS (Lou Gehrig's disease) may benefit because swallowing problems may occur before they reach the terminal phase of their disease.

When are feeding tubes less helpful?

When those in very late stages of dementia lose their ability to swallow, often this is not an isolated event but may represent progression of the disease to a terminal phase. In terminal stages of many diseases including advanced dementia, the gastrointestinal system shuts down and digestion becomes ineffective.

Will my loved one starve?

Some people fear that not providing a feeding tube at the end of life means they are letting their loved one "starve to death."

This is not true. Starvation occurs when a hungry person whose body needs and can use the nutrients is deprived of food. When a dying person's body begins to shut down, the body may be unable to adequately use nutrients that tube feeding would provide, and the chance for bloating and discomfort increases.

A GUIDE FOR DECISION MAKING

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What are some possible complications related to feeding tubes?

Feeding tubes may cause no problems, but some complications have been identified such as: bleeding (1%), infection and skin irritation (1-4%), leakage around the tube (4%), vomiting or nausea (9-10%) and diarrhea or cramping (12%).

Will a feeding tube prevent pneumonia?

Findings from several recent studies of individuals with late stage dementia or advanced terminal diseases show no evidence that pneumonia is prevented with a feeding tube. In some cases, pneumonia risk may be increased with feeding tubes.

Does a feeding tube lower the risk for getting pressure ulcers or help them to heal if they are already there?

There is no evidence that a feeding tube will prevent pressure ulcers or cause them to heal for those who are in advanced stages of a terminal illness. Increased production of urine and stool from tube feedings can increase the risk of pressure ulcers.

Does a feeding tube improve comfort and prevent suffering?

For those with temporary swallowing problems from mouth or throat conditions, tube feeding may alleviate associated pain and provide short term nutritional support. In advanced dementia, the presence of a tube may cause agitation and attempts to pull it out. In some cases, this may prompt the use of restraints which decrease comfort. In the active stage of dying, continued tube feeding may cause fluid overload and make breathing more difficult.

What else should be considered when making a decision about a feeding tube?

It is hard to separate our love and respect for a person from what might be the best decision for that person. Any decision about tube feeding must be made with consideration of general health status and overall goals of care. Prevention of suffering should be a major standard for evaluating individual risks and benefits. Asking the question, "Will the benefit of a tube be significant enough to outweigh any risks and discomfort?" can be helpful.

Clarification of personal, religious and cultural values in the context of overall prognosis and life expectancy may aid decision making.

What choice do I have if I decide not to have a feeding tube?

For those who still have some swallowing ability, careful hand feeding may be tried. For those who are in advanced, terminal stages of disease, maintaining excellent mouth care and providing ice chips or moist swabs will alleviate dry mouth and promote comfort.

Where can I get more information about feeding tubes?

A summary of studies, guidelines, and expert position statements are available at the Coalition for Compassionate Care of California web site: www.CoalitionCCC.org



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