

"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 with advanced illness or age.

Kōkua Mau - A Movement to Improve Care

What is a feeding tube?

Artificial nutrition and hydration is a way of giving liquid and nutrients to people who cannot eat or drink by mouth. Usually, for short-term artificial nutrition and hydration, a lengthy tube (called a nasogastric or "NG" tube) is put through the person's nose and liquid food is put into the stomach. For long-term artificial nutrition and hydration, a tube may be put directly through the skin into the stomach, called a gastric or "G" tube or PEG tube (Percutaneous Endoscopic Gastrostomy) or the intestines (called a jejunal or "J" tube). Sometimes fluids are given through a vein (IV).

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.

When are feeding tubes less helpful?

When individuals lose their ability to swallow or lose interest in eating, this often represents progression of their disease. When this happens, the body is in a natural progression toward the end of life. This normal tendency for the body not to want to eat or drink helps the body to produce its own chemicals (called endorphins) to make itself more comfortable. Sometimes an elderly individual who has not been diagnosed with a disease still begins to lose interest in eating. If the person does not seem to be depressed and there is no other physical cause, this may be a natural process sometimes referred to as "Adult Failure to Thrive".

Will my loved one starve?

Some people fear that not providing a feeding tube means they are letting their loved one "starve to death." This is not true. Starvation occurs when a person whose body needs and can use the nutrients is deprived of food. When a person's body begins to shut down, they may be physically 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%). If the person has difficulty communicating it can be hard to tell if the tube feeding is causing discomfort.

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 (bed sores) 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 skin breakdown.

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, or Adult Failure to Thrive, 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.

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

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. Small amounts of favorite foods may be offered. For those who are not taking food and fluids, maintaining excellent mouth care and providing ice chips or moist swabs will alleviate dry mouth and promote comfort. This is a time for intensive individualized comfort care.

Is there more to know or do?

Your wishes for tube feeding should be indicated on your Advance Directive and/or your POLST (Provider Orders for Life Sustaining Treatment.) Information about Advance Directives can be found at: kokuamau.org/resources/advance-directives. POLST information and the POLST form, which must be completed by a physician, an advanced practice registered nurse (APRN), or a Physician Assistant (PA) licensed in the State of Hawai'i, can be found on the Kōkua Mau website: kokuamau.org/polst.

This document and resources in other languages, such as Advance Directives or POLST, are available from your healthcare provider, doctor, or health insurance company or on the Kōkua Mau website at kokuamau.org/languages

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