



Long Term Tube Feeding

*A Guide for Patients
and Substitute Decision Makers*



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Making a decision about placement of a long term feeding tube in an elderly adult can be difficult. This booklet has questions and answers to help you decide if tube feeding should be started or continued for yourself or for someone you love.

Tube feeding may be offered when a patient cannot eat and drink enough to stay alive, or cannot swallow food or liquids safely. However, if tube feeding will offer no benefit or will be too burdensome, we try to do what is best for the patient without using a tube.

Why Is Tube Feeding Started?

- Swallowing is unsafe because of damage to muscles and nerves
- Inability to eat enough calories or nutrients
- Blockage of the esophagus
(the tube that goes from the mouth to the stomach)
- Severe loss of appetite or interest in eating
- To keep a patient alive long enough to see if he or she can recover from a trauma or illness

What is a percutaneous feeding tube, and how is it done?

The term “percutaneous” means that the tube is inserted through the skin directly into the stomach or small bowel. Once in place these tubes can be used for feeding. Only liquids can be given through these tubes or else they will get blocked.

A specially trained doctor called an interventional radiologist will perform the procedure in the Department of Medical Imaging.

Patients are usually given intravenous sedation and pain-killers while the procedure is being done. They are not given a general anesthetic which means they are not sleeping during the procedure. Local freezing is also used to make the skin numb where the tube goes in. In some cases we need to insert a tube through the nose while the procedure is done; if this is necessary, the nose tube will be removed once the feeding tube is in place.

Once the patient has been given sedation and the skin has been frozen, a needle (the same size as an intravenous) is put through the skin into the stomach. After the needle has entered the stomach a thin wire is passed through it. The needle is then removed, leaving the wire in place. A series of progressively enlarging tubes is then passed over the wire, one after another, gradually enlarging the pathway from the skin to the stomach. Once this pathway is wide enough, the feeding tube is passed over the wire into the stomach and the wire is removed.

Will it hurt?

The local freezing stings a bit when it is injected (and then the skin goes numb). While the procedure is being done it may hurt for a very short period of time, but every effort is made to control pain with intravenous pain-killers. After the tube has gone in, many patients have abdominal discomfort for a few days, but this is usually easy to control with pain-killers.

Are there are risks or complications?

This is a very safe procedure; however, there are some risks and complications that can arise, as with any medical treatment. The main risk is injuring the bowel near the stomach. This happens in about 1 in every 500 procedures done. If it happens, surgery may be needed to fix the injury.

Sometimes fluid can leak around the tube. This can lead to the skin around the tube becoming very red and sore. If this happens the tube may need to be removed.

How Are Tube Feeds Given?

- Liquid formula is put into a bag attached to the tube. The liquid goes into the stomach either at mealtimes as a bolus, or continuously using a pump, at a slower rate
- The clinical dietitian recommends the liquid type, rate, and schedule of feeds
- Most medications, crushed or liquid, can be given through the tube



What Are the Benefits?

- Provides enough calories and nutrients to meet a patient's needs
- Reduces choking on food
- Medications can be given easily through the tube
- Tube feeding may improve survival for reversible illness or acute medical conditions e.g. sepsis, stroke, gastrointestinal obstruction

What Are The Burdens?

- Tube feeding may feel uncomfortable. Patients need to sit in an upright position or have the head of the bed inclined during feeding and for a period of time after to help prevent aspiration
- Some patients become agitated and try to pull the tube out. Then they may require sedation or hand restraints
- Some patients have looser bowel movements or skin irritation around the tube
- Increased fluids may make it harder to breathe
- Mobility may be limited because of the tube feeding apparatus or schedule
- Some patients may not want to be seen as sick and helpless around their friends and family
- Tube feeding does not improve survival for patients with advanced dementia or advanced cancer
- Placing a feeding tube into a patient's stomach will not stop aspiration (breathing in food/fluid)

What Are the Treatment Choices?

Supportive Care + Feeding tube placement

or

Supportive Care

Supportive Care involves:

- Careful hand feeding by trained health-care professionals or family members, for those who can swallow some oral food and fluid. Swallowing studies (typically involving x-ray) may be used to recommend proper positioning, consistencies, and techniques for comfort feeding.
- Providing comfort by:
 - keeping the mouth moist (with ice chips or water) and clean
 - controlling pain with medication
 - providing oxygen
 - offering spiritual and emotional support

Are There Guidelines To Help Make A Decision?

- Giving oral food and fluid is part of the normal care offered to patients. In contrast, tube feeding is an optional medical treatment.
- It is acceptable for a patient or substitute decision maker to refuse tube feeding. Canada does not have a law that states that tube feeding must be provided for people unable to eat and drink enough to stay alive.
- Decisions about tube feeding should consider the benefits and burdens to each patient, physical and emotional condition, culture, religion, and personal values.
- Tube feeding is not recommended when a patient is permanently unconscious, terminally ill (including advanced dementia), or not wanting to be tube fed, for any reason. Not being able to eat may be nature's way of letting someone slip away.
- Tube feeding is not urgent if a person is getting water, either orally or by intravenous.

Who Decides?

- The patient makes the decision if they are able to understand the benefits and burdens of tube feeding.
- When a patient is not able to make the decision, substitute decision makers should follow the patient's wishes or do what is best for the patient if the wishes are not known.

What Would Your Family Member Want?

- Advance Directives (or living wills) describe what life supports a patient wants or does not want if anything happens to him or her. Has he/she ever expressed their wishes about the use of feeding tubes?
- Consider the values of the patient when he/she was well. Would the patient choose to get a feeding tube in this situation?
- The decision does not have to be the same as what you would choose for yourself in the same situation.

What About Stopping?

- After a patient begins tube feeding, you may meet with members of the health care team to decide whether to keep the feeding tube or stop. You can ask for a meeting anytime you want to talk about changing the plan.
- Remember that patients will be kept safe and comfortable whether they are having tube feeding or not.
- Reasons for discontinuing feeding are:
 - The patient has improved and is able to resume eating
 - The patient is worse and the tube may no longer in their best interests

Who Can I Talk To About Making This Decision?

Discussion with patient, family, doctors, and nurses is encouraged. You may also want to speak with the chaplain, social worker, dietitian, speech-language pathologist, or hospital ethics consultant. Your doctor or nurse can help you contact any of these people to help you make your decision about tube feeding.

This booklet has been revised for the Veterans & Community program

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