ADVANCE CARE PLANNING



Tube Feeding Decision Aid

There may be a time, due to serious illness, injury, or accident, when you can't get enough nutrition or are unable to eat by mouth. This guide will help you figure out your ideals, goals, and priorities for care if you need to decide whether to begin tube feeding.

In what situation would I need to plan for tube feeding?

Sometimes a person is sick or injured and they cannot eat because of swallowing problems. Or they can eat but can't get enough nutrients from the food. Or the food does not move well through their stomach or intestines. Regardless of the situation, making the choice to use tube feeding can be difficult. It is important to take the time to learn about tube feeding, think about what your goals are, and figure out if tube feeding meets your goals.

What are some examples of when tube feeding would be necessary?

- · You have head, neck, or throat cancer, which makes it difficult to swallow safely
- You have damage or injury to your brain from a disease
- Your throat muscles are weak, making it difficult to swallow, most often due to Lou Gehrig's disease (ALS) or other conditions that affect your throat muscles
- Long-term effects from a stroke

When should I make my decision?

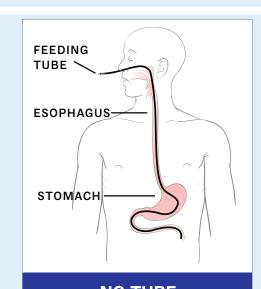
Start deciding now. It's best to decide before you need tube feeding so you can say what you want. There is no time frame for when you need to decide. This is a big decision and takes time. You want to be able to make your decision while you can still discuss it with the people closest to you.

What is tube feeding?

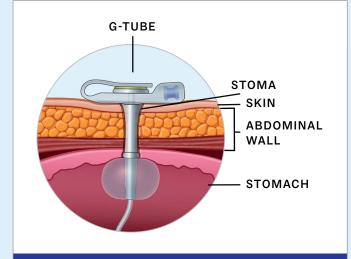
A feeding tube is a medical device used to provide nutrition. Tube feedings are given when you cannot eat enough to have plenty of nutrition for the body. Nutrition is needed to help the body heal, and fluids are needed to keep the body hydrated.

A gastrostomy [gas-TROS-tuh-mee] tube (GT) is a short feeding tube that goes directly into your stomach through a small surgical incision called a stoma [STOH-muh]. The GT is soft and bendable. An NG tube is a short thin feeding tube that goes into your nose and down into your stomach to deliver feedings. It is also soft and bendable. Liquid food (nutrition) is then put into the body through these tubes.

- Your doctor may order individual feedings through the tube at various times of the day (bolus feeds), or you may have a pump that feeds you smaller amounts continuously.
- You will not be able to "taste" your liquid food.



NG-TUBE A soft, bendable tube is inserted into your nose, down your esophagus to your stomach



Requires a surgical procedure to create an opening on the outside of your body where a tube is inserted into your stomach

G-TUBE

When does tube feeding work best?

Tube feeding may help you stop losing weight or help you maintain your weight. It works best if you are healthy enough (even with your illness or disability) or your illness or disability makes it hard to swallow or maintain healthy calorie and nutrition intake.

It may not help you if your body is failing despite treatment, and death is likely to occur soon.

What is the process for delivering the feed through the tube?

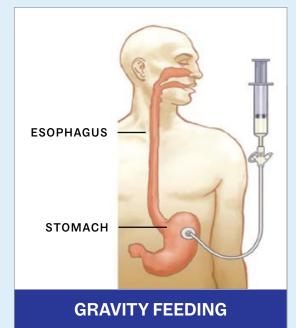
Types of feed (nutrition)

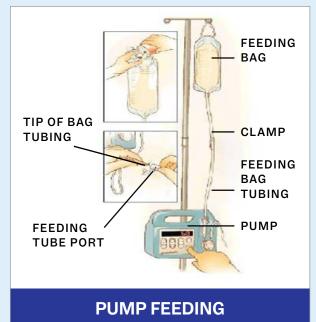
There are many kinds of tube feeds based on what your needs are.

There are tube feeds that are specially designed for those with diabetes and kidney problems, those needing more protein, and those needing just more calories in general.

How a feeding is done

A dietician will follow your case and determine the best method to deliver your tube feedings. Examples include a continuous infusion using a pump, or a bolus feeding in which a syringe is attached to the end of the feeding tube, and the liquid nutrition is poured into it. Gravity is then used to move the liquid from the tube into the stomach.





What are the side effects?

Mechanical problems may include a blocked or displaced tube, knotted tube, tube that is pulled out accidentally, obstruction, or hemorrhage. Infection can occur at the tube-insertion site, lungs (aspiration pneumonia), throat & ears, the area outside the stomach & intestines, & GI tract. Metabolic problems may include electrolyte imbalances, low or high blood sugar, and vitamin and mineral deficiencies.

PROBLEMS OF LONG-TERM FEEDING TUBES 1	% FREQUENCY	NOTE
Diarrhea	30%-80%	Nine (9) times more likely to have bacteria that causes diarrhea (<i>C. difficile</i>)
Clogged tube	23%-35%	
Liquid food leaks	13%-40%	
Nausea / vomiting	10%-20%	
Risk of death (up to 30 days post-placement)	7%-26%	Up to 54% in patients with dementia; 63% at 1 year ²
Tube site infections	4%-30%	
Reflux	0.4%-6%	Depends on tip of tube replacement
Serious leakage	0.4% – 4.4%	Leakage into areas outside the stomach or intestines, stomach bleeding, injury to internal organs
Constipation	Less common than diarrhea	
Lung complications	Abdominal swallowing or reflux significantly increases the risk for pneumonia from aspiration (breathing fluid into your lungs) within 1 month of tube placement.	

Can others help me with the feeding tube?

YES. You and your caregivers will receive education, hands-on training, and support to safely manage your feeding tube and nutrition.

Does it hurt to have the tube put in through my abdomen (belly)?

The tube is thin and flexible. Usually, placement of a long-term tube involves minor surgery. However, medications will be given to help with the pain during and after placement. For a short-term tube, it is generally placed in the nose and doesn't require surgery.

Will the tube be visible to others?

Clothing covers the long-term tube when you are not using it. You may feel uncomfortable in tight-fitting clothing, so you may find it easier and more comfortable to wear loose-fitting clothing. A short-term tube is visible because it is inserted into the nose.

Can I change my mind if I decide to try tube feeds and don't like it?

You can always change your mind. You may decide you want tube feedings at first, but your feelings could change during treatment. It is important to express your wishes about potential future situations in which you would or would not want to continue tube feedings. You will want to write these decisions down in an *Advance Directive* and share your wishes with your doctor and healthcare agent.

What could happen if I stop or refuse tube feeding?

- You may feel thirst, hunger, or nausea.
- You may feel weak, drowsy, or confused.
- Your mouth and lips may feel dry or sore. However, ointments and swabs are available to help keep your mouth and lips moist. In any scenario, every effort will be made to keep you as comfortable as possible.

What do I need to do now?

Tube feeding is one of many choices you can make to live well if that is a goal for your healthcare. You should:

- \square Read this guide to learn about tube feeding.
- \square Reflect on what is important to you and what your goals of care are.
- ☐ Tell your healthcare agent, your family, and your doctor what you decide.
- □ Complete an *Advance Directive* and give a copy to your doctor, your hospital, your healthcare agent, and any other person who may need to know this information.
- ☐ Review your *Advance Directive* every year to figure out if your document reflects your current wishes.
- 1. Blumenstein, I., Shastri, Y., & Stein, J. (2014). Gastroenteric tube feeding: Techniques, problems and solutions. World Journal of Gastroenterology, 20(26), 8505-8524. doi.org/10-3748/wig.v20.i26.8505
- 2. Potack, J. & Chokhavatia, S. (2008). Complications of and controversies associated with percutaneous endoscopic gastrostomy: Report of a case literature review. The Medscape Journal of Medicine, 10(6), 142



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