CYSTIC FIBROSIS FOUNDATION®
ADDING TOMORROWS™

Improving Nutrition with Tube Feedings

Many adults with Cystic Fibrosis use tube feedings to support their nutrition. This section will help you understand why and how tube feeding can help you.

You have heard from your CF care team, your parents, and others all your life about how important it is to increase the calories you eat to help with weight gain and girth. You know all the tricks to adding calories to your meals. Often the amount you need to eat is greater than how much you can eat. Many people with CF need to take in double the calories of their friends and family who don't have CF. This is where support from tube feeding can be helpful and help ease the burden of needing to eat so much. Extra nutrition by a tube feeding can help you meet your nutrition goals determined by you and your CF care team.

Extra nutrition can not only increase your weight but it can lead to improved ability to fight infection and improve your energy.

It is important to discuss all changes in your care with your CF medical team. This section will help you educate yourself and understand how tube feeding can ultimately help you.

In this section,

- learn about tube feeding – when is it time for a feeding tube, what kinds of tubes there are
- learn how to manage a feeding tube
- work with your CF team- proper supplements, insurance coverage

Learn about feeding tubes

When do I really need a tube?

There are many personal and medical reasons you may chose to have a feeding tube placed. You may have a goal of wanting to gain weight or just maintain a certain weight.

There are many reasons for having healthy weight goals. There has been good evidence from population-based studies that normal ranges of weight and height were associated with better pulmonary function. This translates into a BMI (body mass index) of 22 for women and 23 for men. Your dietitian can explain what your BMI should be. Increased weight gain can increase your energy, possibly reduce exacerbations of your lung disease, and allow you to have better exercise workouts to increase your endurance and strength. If you would like to calculate your BMI, go to http://nhibisupport.com/bmi.

Your healthcare team wants to work with you to keep you healthy. They will help you get the most out of your nutrition through supplements and appropriate use of pancreatic enzymes.
There may be factors in the way of you being able to achieve adequate weight.

Some factors that might affect you include:

- **Poor appetite -** If your appetite is always poor or you can't physically eat the amount of food you are used to (which leads to weight loss, muscle loss and getting sick more often), extra nutrition through a feeding tube might be right for you. Your appetite can be reduced for many reasons but when you do not have the desire to eat, your calorie intake goes down. CF lung disease may make your lungs expand and get in the way of your stomach being able to stretch after a meal; therefore eating large portions may be difficult for you.
- **Nausea or vomiting** -If you often vomit from coughing and/or have severe heartburn, you may want to consider extra calories with a feeding tube.
- **Worsening lung function** – If you are unable to regain weight that was lost when you were sick or you are trying to reach a good weight for lung transplantation, tube feeding is an option.

What kind of tubes are there?

Gastrostomy Tube (G-tube): The most common feeding tube is the gastrostomy tube, also called a G-tube or a percutaneous endoscopic gastrostomy (PEG) tube. It is a flexible tube that is inserted directly into the stomach through an incision in your abdomen. This allows nutrition to be delivered directly into your stomach.

Low profile "Button" G- tube: After a few months of healing from the G-tube placement, your doctor may recommend replacing the tube with a "button". This device is flatter and lies against the skin of your abdomen. This can easily be placed once the G-tube site is healed, usually about 8 to 12 weeks after you have had the G-tube placed. This time may vary at you hospital. The button can be opened for feedings and closed in between feedings or medications. For many, the transition to a button makes tube feedings and care easier and more convenient. Some hospitals may place the button without inserting the G-tube first.

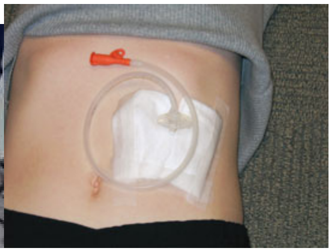
Nasogastric Tube (NG Tube): A nasogastric tube is a thin, flexible tube that goes in your nose, down your throat, and into your stomach. This is the least invasive type of feeding tube because inserting an NG tube does not require a surgical incision. These tubes need to be inserted each night and then taken out in the morning for overnight feedings.

Jejunostomy Tube (J-tube): A jejunostomy tube, also called a J-tube, is inserted through an incision in the abdomen directly into the section of your small intestine called the jejunum. It bypasses the stomach. J-tubes are used if a person cannot tolerate feedings directly into the stomach.

Gastrostomy-Jejunostomy Tube (GJ-Tube): A Gastrostomy-Jejunostomy tube, also called a GJ-tube, is a tube that is inserted through the abdomen into the stomach, but does not stop there. The GJ-tube passes through the stomach into the jejunum, delivering the feedings directly into the small intestine just as they are with a J-tube.

What will the tube look like on me?


Button


PEG tube

How to Manage Your Feeding Tube

What goes through the tube?

Usually the same supplements your health care team has prescribed for you to drink can go through the tube to nourish you. There are brand name products and generic supplements that are both found over the counter or through your home care or medical equipment company. There are also tube feeding products that are specialized for different needs of the person.

How do I give the feedings?

Everything is individual! You will work with your CF care team to make a schedule that works best for you. Some choose to give tube feedings during the daytime, nighttime, only between meals or all day. Some feedings can be delivered with a pump, a hanging bag or using a large syringe. Overnight feeding can range anywhere from six to 18 hours each night.

You will need to take pancreatic enzymes with your tube feeding to help you absorb the nutrients: protein, fat, vitamins and minerals. Your dietitian will discuss with you the best way to take your enzymes. The main goal is to prevent malabsorption (oily, multiple, light-colored stools) and promote weight gain.

Will there be any problems?

With any new therapy there may be concerns that come up and your team can help you trouble shoot them.

Nausea and Vomiting

- Possible causes:
    - Medications
    - Something is blocking the intestine
    - Tube is not positioned correctly
    - Tube feeding formula, rate or amount may not be ideal
- What to do:
    - Reduce the rate of the tube feeding
    - Space the tube feedings farther apart
    - If nauseated, hold feedings until symptoms subside
    - Check the amount of liquid you have in your stomach prior to feeding. This is done with a syringe. Your CF care team will give you guidelines when to hold your tube feeding
    - If you feel you will vomit, leave tube open to drain
    - Call your health care professional if nausea and vomiting prevent you from getting your full feedings for more than 1 day

Constipation (decreased frequency or hard to pass)

- Possible causes:
    - Inadequate fluid intake or skipping feedings
    - Physical inactivity
    - Not enough fiber
    - Medications
- What to do:
    - Check that you are taking the prescribed amounts of tube feeding formula and water flushes
    - Do not skip feedings
    - Participate in physical activity (walking)
    - Try ½ cup prune juice flushed with ½ cup water down tube 1-2 times per day
    - Call your health care professional if you are constipated for more than 3 days

Diarrhea (loose, watery, frequent stools)

- Possible causes:
    - Tube feeding rate is too fast (especially if you have a J-tube or small bowel tube)
    - Not enough pancreatic enzymes
    - Tube is not positioned correctly
    - Lack of fiber in diet/tube feeding
    - Medications
    - Bacterial contamination of feedings, virus, or infection

- What to do:
    - Decrease tube feeding rate
    - Increase water flushes by 2-3 cups per day to replace losses in the stool
    - Keep unused, opened formula covered in refrigerator for only 24 hours; discard if not used
    - Use clean techniques for storing and giving feeding
    - Discontinue use of laxatives or stool softeners
    - Call your health care professional if diarrhea occurs for more than 6 times a day

Clogged Tube

The tube should flush with some resistance, but you should be able to give feedings, water flushes, and dissolved medicines without difficulty.

- Possible causes:
    - Tube older than 2 years
    - Tube that has a small diameter or tube that is very long
    - Not flushing the tube after feedings or medications
    - Not dissolving medications well
    - Not flushing the tube after checking residuals
- What to do to prevent a clogged tube:
    - Replace old tubes as directed by your doctor
    - Flush with at least 60 mL of warm water after feedings, medications, and residual checks
    - Do not put any solids or foods through your tube
    - If your feedings begin to run in slower, irrigate the tube with water more often
- What to do if your tube clogs:
    - Push 30 ml of warm water through the tube using a pumping motion with the syringe (you may need to do this 3-5 times before clog begins to move)
    - Try to move the contents of the tube by pulling and pushing the syringe barrel several times
    - Pump air through the tube using the syringe (may need to do 3-5 times)
    - You may use small amounts of carbonated beverages to unclog the tube; however, speak with your dietitian or health care professional before using products other than warm water
    - Call your health care professional if none of the above methods work to unclog your tube

Skin irritation around the tube

- If area is red and sore, clean area with soap and warm water. Rinse around area with plain water and pat dry. You may use an antibiotic ointment around the site.

- If any areas appear crusty, gently soak or scrub the crusty areas with soap and warm water on the skin and tube itself. If you prefer, you may use a solution of ½ hydrogen peroxide and ½ water applied with a cotton swab to help clean these areas. After cleaning, rinse with plain water and pat dry. You may use an antibiotic ointment around the site.

Feeling full in the morning-unable to eat breakfast

- Wait about 2 hours after you stop your tube feeds before eating breakfast.

  - Slow down the rate and start the tube feedings earlier in the evening, lengthening the time of the feedings

How quickly will I gain weight?

You will work with your dietitian and CF team to set calorie and weight goals. These should be based on your daily schedule and your overall health goals. Unfortunately when you lose weight you may be losing muscle along with body fat. Safe weight gain should include muscle gain and not just body fat gain. This will best be helped when you continue to exercise and maintain muscle with activity.

Work with Your CF Care Team

Everyone plays their part in answering questions and helping you through this process.

- Your physician can discuss the benefits and overall health goals and can also direct the kind of tube placement you may need.
- Your RN can assist you with equipment and helping trouble shoot any problems. They will help educate you on the care of your tube. They can also help you with insurance questions.
- Your dietitian will help you find the correct formula, calorie level and schedule for you. They can also help educate you on the care of your tube.
- Your Social Worker helps with insurance questions and can discuss your feelings about this process.

Will insurance cover any cost?

Working with your CF care team and knowing what your health insurance plan will cover is key. Some insurance companies cover the equipment that is needed but not the tube feeding product. This will need to be taken into consideration as you are deciding whether a feeding tube is right for you.

How can my family and friends help me?

Education for your family and friends on the entire process will help you become successful. When others understand what and why you are making this decision it is easy for them to help. Your team is happy to educate anyone that will be instrumental in your care.

Making the decision to have a feeding tube placed is a personal decision.   Information and assistance from your CF care team will help you make the right decision to improve your health.