Understanding tube feeding for patients with Cystic Fibrosis
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In some cases, children with Cystic Fibrosis (CF) find it difficult to gain weight or grow normally even if they take their enzymes and follow a high calorie diet. This is generally because they have increased work of breathing, difficulty absorbing food and use extra energy to fight chest infections.

A child with CF may need up to one and a half times more calories each day than a child who does not have CF. Higher body weights are linked to better lung function so maintaining a healthy weight is important for their overall health. If a child with CF is having trouble gaining weight by eating alone, tube feeding may be suggested by the CF team to help meet their energy needs.

If a feeding tube is suggested, it doesn’t mean that a child is a ‘bad’ eater or their parents have failed in some way to get them to put on weight. It can be very difficult for a child with CF to eat enough calories in a day to meet their high needs, especially during times when they don’t feel well. Sometimes so many calories per day are needed that it is impossible to get them all in by eating!

Often kids and their parents don’t like the idea of a feeding tube when it is first discussed. Various other strategies can be tried to help with weight gain before a feeding tube is recommended, however sometimes these are not enough. Usually weight gain and growth get back on track very quickly after placement of a feeding tube and the benefits of improved nutrition follow. Once a feeding tube has been placed families often feel relieved as they no longer have the pressure of having to focus on eating so much every day.

The extra calories provided from tube feeds can lead to improved weight gain and growth, higher energy levels, better lung function and an increased ability to fight infections. Tube feeds are often done at night during sleep and usually aim to provide around 30–50% of total energy needs. Tube feeds are not meant to replace eating but are used in addition to a high energy diet during the day. Higher body weights are linked to better lung function so maintaining a healthy weight is important for their overall health.
Understanding tube feeding for patients with Cystic Fibrosis
How does it work

Generally the type of feeding tube used in children with CF is called a gastrostomy feeding tube, often referred to as a PEG. PEG stands for Percutaneous Endoscopic Gastrostomy. A soft tube is placed directly into the stomach through the abdominal wall during a minor procedure under anaesthetic.

Figure 1: Diagram of a PEG (Percutaneous Endoscopic Gastrostomy) tube once it has been placed in the stomach

Figure 2: Picture of a PEG (Percutaneous Endoscopic Gastrostomy) tube external to the stomach
The initial procedure is usually very quick, and the patient is usually able to be discharged from hospital within a few days. After about 3 months, this tube is changed to a “button” which is a low profile gastrostomy device that sits flush with the skin. A button can be easily hidden under clothing so no one would even know it is there!

Figure 3 and 4: Pictures of a low profile gastrostomy device (“button”) external to and in the stomach

The skin around the gastrostomy tube requires cleaning every day. This can just be done with soap and water in the shower or bath. People with a PEG can still do all their normal daily activities, including bathing and swimming. Tube feeds are generally given overnight so that children can do all their normal activities during the day (including eating!)
A parent’s story—‘my daughter’s experience with tube feeding’

Rebecca had her PEG placed one year ago. Around eight months went by between when the PEG was first suggested to Rebecca and her family by the CF team and when she eventually had the procedure. Rebecca’s mum reports that she finally made the decision to go ahead with the PEG because Rebecca was “skin and bones.” “No matter how many calories I got her to eat, it wasn’t paying off with weight gain. At one point I made her a really high calorie 1 litre chocolate milkshake every night and she only put on 200g that whole month!”

“At first I felt very negative about the PEG; it seemed like another thing we would have to do. Eventually I realised it had to happen for her health.”

One year down the track, Rebecca’s mum reports she “loves the PEG!”

“Food has returned to just being food. I no longer feel like I have to constantly nag Rebecca about eating all the time. She has put on weight and she looks so much better! The feeds are easy to do, the formula is pre-packaged and we just hang it up every night.”

“Surprisingly her appetite is actually much better now than before she had the PEG! If she has a night off of feeds now she is actually less hungry the next day. If I could go back in time, I would definitely still choose to go ahead with the PEG but I think Rebecca probably needed much of the time we waited to get used to the idea. My advice to other families considering tube feeding would be that it’s not as bad as you think it’s going to be and it is a huge relief once you have the overnight feeds to rely on.” In the first 4 months after Rebecca had her PEG placed she put on 6kg! Her weight is now tracking on the percentile chart and in proportion to her height.
Figure 5: Rebecca’s weight and height percentile charts
Frequently asked questions

How and when do you give tube feeds?
Most commonly, tube feeds are given overnight while you are asleep. A tube feeding formula is continuously trickled into the stomach for 8–10 hours via a pump. This allows you to eat and drink normally during the day. Sometimes tube feeds may be given as bolus feeds during the day while you are awake instead of, or in addition to, overnight. These bolus feeds would be given after or in between meals so you still have an appetite for eating and drinking.

What is tube feeding formula and what type will be used?
There are many different types of tube feeding formula available. Tube feeding formulas are similar to infant formulas but made to suit older children and adults. They are generally milk based liquid supplements that contain calories, protein and carbohydrate as well as vitamins and minerals. A standard tube feeding formula will be selected by your dietitian, depending on your individual needs. Some people require a specialised formula, for example if they have allergies, or if their body is unable to absorb a standard formula effectively. This will be discussed with you by your dietitian.

Will I still be hungry?
Most people that have overnight tube feeds aren’t hungry for breakfast when they wake up in the morning but their appetite returns around mid-morning ready for recess or morning snack. Tube feeding is meant to supplement eating not replace it, so remember to continue to try and eat and drink well over the day and evening. Sometimes people that have a feeding tube placed report their appetite during the day is even better than before they had overnight tube feeds!

Do I need to take enzymes for my tube feeds?
If you are recommended a standard tube feeding formula by the dietitian, you will need to take enzymes to help absorb the nutrients and fat in the formula. Your dietitian will advise you about when and how to take enzymes, as well as how many you will need. Generally a dose of enzymes is taken when the tube feed is started at night and another in the morning when the tube feed is turned off. It can also be of benefit to take an extra dose during the night if you happen to wake up, but this is not necessary if you sleep through the night. The number of enzymes you need to take will be based on the fat
content of the formula, just like the number of enzymes you take during the day is based on the fat content of the food you are eating.

**Where do I get the tube feeding formula and how much does it cost?**

Your tube feeding formula will be provided on prescription and in most cases will be delivered to your home by the formula company each month. The cost of the formula is the same as any other prescription fee. The equipment needed to run the overnight feed is also home delivered by the formula company. All equipment from the home equipment centre is capped at $50 per month.

**Will I need to have tube feeds for the rest of my life?**

How long you will need tube feeds for depends on how well you are and how quickly you are able to reach and maintain your goal weight. Most people that need a feeding tube continue to require the tube to maintain a healthy weight for a long time. During this time however, you may not need to use the tube every night. If you are well and at your goal weight, you may be able to decrease the number of nights per week you use the tube. After a while, some people may only need to use their feeding tube during times when they are unwell or are finding they are unable to eat enough to gain weight or maintain a healthy weight.

**Does anyone ever have their PEG removed?**

Occasionally yes, a very small number of people who are able to maintain a healthy weight for a long period without using their PEG tube have had their tube removed. After a successful lung transplantation many patients have their PEG removed as they no longer require such a high calorie intake.

**Are there any side effects?**

There are a few possible side effects but they are all very manageable. The most common is the feeling of fullness in the morning after having had the feeds through the night. Most people just manage this by not eating breakfast or having their breakfast a few hours later than usual. Sometimes, a person who has just started having tube feeds may develop softer or looser stools. This can be corrected by slowing down the rate of the feeds or changing to another type of formula. Another less common side effect is skin irritation or pain at the PEG site which may be due to leakage or infection around the PEG site. These issues can usually be easily treated by changing the button or prescription of oral or topical antibiotics.
For further information

The Children’s Memorial Hospital in Chicago has made DVD about PEG feeding in CF patients; it is accessible at the link below: www.childrensmemorial.org/depts/pmcc/cysticfibrosis/tubefeeding.aspx

The Northern England CF Consortium also has online videos you can watch about tube feeding at the link below: www.nnecfc.org/videos.htm

Acknowledgements

The Children’s Memorial Hospital in Chicago for the concept for this resource. You can view more patient stories in the Chicago resource on tube feeding at the following website: www.cff.org/treatments/Therapies. Click on the ‘tube feeding’ link under the ‘Nutrition and Eating Right’ heading.