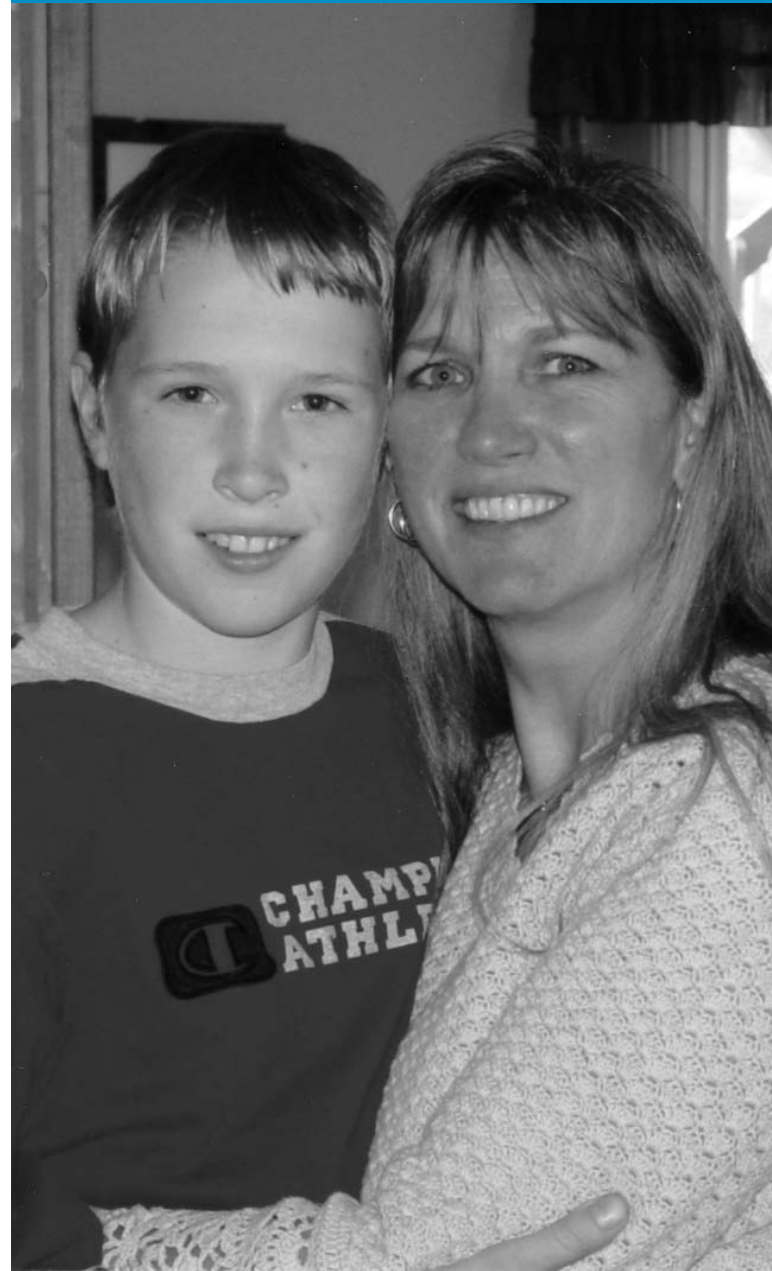



Supporting Nutrition: Understanding Tube Feeding



Families from the
Children's Memorial
Cystic Fibrosis Center
share their experiences
with tube feeding


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Memorial
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Supporting Nutrition: Understanding tubefeeding



Above: Maggie, CF Center patient with Cathy O'Malley, respiratory therapist.

Front cover: Kyle, a CF Center patient, and his aunt Nanci.

About this booklet

This booklet contains personal perspectives from individuals who know about tubefeeding firsthand. It was created by the Cystic Fibrosis Center at Children's Memorial Hospital in Chicago which has been accredited by the Cystic Fibrosis Foundation since 1963.

The Center is staffed with a dedicated, multidisciplinary medical team, which includes pediatric pulmonary physicians, nurses, nutritionists, respiratory therapists, pulmonary diagnostic specialists, social workers, medical psychologists, genetic counselors and exercise physiologists.

On behalf of the CF Team, we thank our patients and families for their thoughts, photographs and time, and acknowledge their commitment to helping others.

Eileen Potter, MS, RD
Susanna A. McColley, MD
Cystic Fibrosis Center
Children's Memorial Hospital

Why tubefeeding is beneficial for children and adults with cystic fibrosis

When it comes to managing cystic fibrosis, maintaining nutritional health is essential. Most individuals with cystic fibrosis (CF) can achieve and maintain a healthy weight by planning their meals and snacks, choosing nutrient-dense, calorie-rich items and taking enzymes. However, if gaining weight is a struggle, tubefeeding is a healthy option.

Gastrostomy tube (G-tube) and nasogastric (NG) tubefeeding are two ways to supplement food intake without having to eat or drink. Both can be used to deliver generous calories and nutrients while sleeping at night or during the daytime. The G-tube is inserted directly into the stomach and a small tube is always present on the abdomen. With NG tubefeeding, a long, thin, soft tube is inserted into the nose until the tip rests in the stomach. The NG tube can be removed in the morning and reinserted every night.

Extra calories gained from tubefeeding can lead to weight gain and growth, improved energy and self-image, improved lung function

and the ability to fight infection. Many parents of cystic fibrosis patients feel relief that they no longer have the pressure of trying to get their child to eat more every day. With tubefeeding, quiet toddlers become energetic and school-aged children start to enjoy mealtime again. Teenagers gain confidence from a new physique and the changes that come with puberty. Adults and college students have the stamina to work and study hard.

Quite often, months go by while a variety of eating strategies and enzyme adjustments are tried. Although this is an important step, tubefeeding should not be considered the “last resort.” Nearly all CF patients who try tubefeeding get on track quickly and experience the benefits of improved nutrition. Following are the experiences of four families who tried tubefeeding and through it found a new way to maintain nutritional and physical health.

For more information on tubefeeding...

Please contact your CF Center dietitian:

Name: _____

Phone: _____

A mother's perspective

Amy shares her experiences with the nutritional challenges that faced her daughter, Juliana.

“Juliana was diagnosed with CF at 19 months of age. Her diagnosis came as a result of her poor growth pattern and symptoms of malabsorption. Upon beginning treatments she gained a small amount of weight but very quickly began to refuse most foods. By the end of her second month after diagnosis she would no longer drink milk, which is one of the cornerstones of any high-calorie diet. She was well below all the curves on the growth chart and not making any progress.

“Dr. Susanna McColley [Head, Children’s Memorial Department of Pulmonary Medicine; Director, Cystic Fibrosis Center] brought it to our attention that Juliana needed a rather large daily intake of calories to bring her up to the lowest curve on the growth chart. This amount of calories did not include those much needed to help her fight off infection on a day-by-day basis. It became clear to us that she was not capable of taking in so many calories because she simply did not feel like eating, and we could not force her. Feeling very distressed by the helplessness of the situation, we needed some means of boosting the number of calories she took in without putting stress on her to eat more than she felt she could.

“At first mention of a G-tube, my husband and I had the same negative response. I could not imagine doing that to my daughter. After the clinic visit when the tube-feeding was mentioned, I came home determined to get Juli to eat and gain some weight. However, Juliana was not so inclined. At our next visit she had not made any significant gains, and I realized that the older she got, the further behind she was getting.

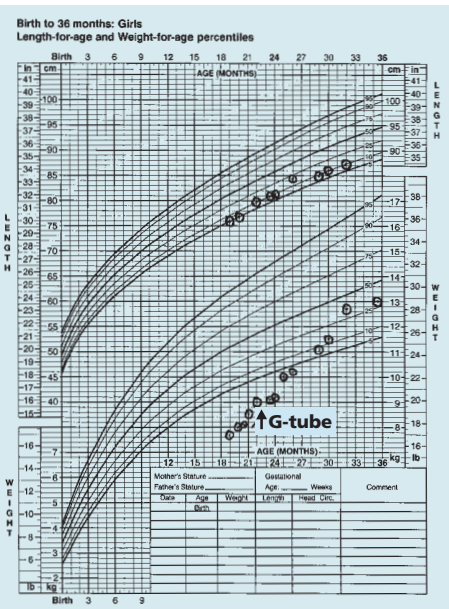
“Out of sheer frustration and desperation I asked Dr. McColley to talk to us in more detail about the G-tube. She said she happened to have a young lady with CF in the office at the moment who had a G-tube, and she felt sure she would be willing to show it to us and talk to us about it. Maggie, though petite, was the picture of health. With a smile on her face, she showed us the ‘button’, and laughing told us that she wears a bikini without shame. She told us about cheerleading and other activities. She also explained that, although she always takes a lunch to school, sometimes she just doesn’t feel like eating. On those days she goes to the school nurse and receives a ‘bolus’ feeding through her tube. All I could think was that I wanted my daughter to have that kind of energy and the backup support of an alternate means

of getting those precious calories when she just could not do it on her own. We were expecting her to do something of which she was not capable, and the G-tube would get it done for her. I realized this is just one more thing I can do to help my daughter fight this disease. It is just as needful for her as enzymes or chest PT.

“At 3 years old, Juliana is now back on the growth chart and more energetic than we ever thought possible. The G-tube is not for all CF patients, but in Juliana’s case it has been a lifesaving miracle. We thank God for Dr. McColey and the CF team at Children’s Memorial who were willing to patiently work with us until we were ready to do what they knew was best for Juli all along.”



Before tubefeeding, Juliana (pictured on right with sister Jenna) was well below all the curves on the growth chart.



Juliana is now a healthy and energetic toddler after one year of tubefeeding.

A teen's decision to try NG tubefeeding

Kyle and his parents, John and Caryn, describe how NG feeds have helped Kyle meet his goals.



From Kyle, age 15: “When the first talk of tubefeeding came up, thoughts on my mind were, ‘I hope I don’t have to do this’. But as the conversations went on, the thought that this might be the solution to my problems came up—it might do wonders for me. It seemed

so weird and unnatural. The thought of me sleeping with a tube in my stomach was a little discomfoting, but I thought it may do everything I want for me.

“Putting the tube in was very difficult for the first week—it took about two weeks to get used to it, and sleeping with it took longer, about a month. Sleeping with it doesn’t hurt, it is just unusual. Working tubefeeding into my day is not that hard. Having everything set out and organized makes the process of getting set for bed a lot easier. It’s just an extra step to do before I go to bed, like brushing your teeth, and it becomes that simple after you come up with a good system.

“Tubefeeding has helped me so much. I’ve gained over 25 pounds and grown four inches in less than one year. Even my look has changed—I don’t look so scrawny anymore. It has also helped me realize that you should take scary ideas head on because they may not be as they seemed at first. I don’t advertise the tube to my friends. If they ask, or I feel someone should know about it, I tell them. It is not a big deal for me to talk about it.

“My advice for others is to try everything possible with normal diet. If that fails to help you, don’t be afraid to try the tube. It will give you so much satisfaction. It will help you so much in the long run and you will notice a considerable difference in weeks. It’s tough at first, but if you stick with it, it can do so much for you.”

Above: Kyle with his NG tube in place;

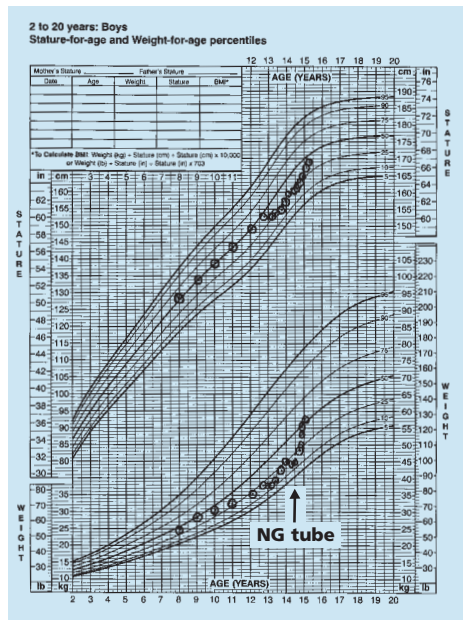
Right: Kyle is very active in sports, including competitive water skiing.



From Kyle's mother: "When the CF team brought up the tubefeeding discussion, at first I felt defeated because we had tried so hard to get Kyle to gain weight. He was eating all high-calorie foods and lots of them, yet he just wasn't gaining. I felt like I had failed to get him to gain the weight. However, the CF team worked with us for many months to have Kyle gain weight in other ways, including different foods, higher calories, different enzyme levels and different ways of doing things, yet it just didn't seem to work. I never felt pressured to turn to the tubefeeding until we felt ready. Actually, it was Kyle who made the decision. I still don't think I was comfortable with it at that time. But in hindsight, it's the best decision that we made in a long time.

"The weight just started to come on. I remember the times when we would come for clinic and I would just hope that he at least stayed the same. I think Kyle feels better about himself because he has a bit of 'meat' to his bones. His face has filled out and he has a better look to him. Kyle also seems to be taking responsibility in a larger way toward his health since the tubefeeding has started.

"My advice is to not be afraid to give the tubefeeding a try. I feel that we lost a lot of time by not trying it earlier in our care. I feel relief with the tubefeeding that I don't have to make him pound down all the extra calories during the day, he has the night that works for him now, too. Tubefeeding is a tremendously effective technique. It adds another dimension to daily care but it's well worth the effort."



Kyle's growth chart

G-tubes and body image: A teen's perspective

Maggie was 9 years old when she received her G-tube. She and her mother, Kerry, explain the benefits of tubefeeding.

From Maggie, age 16: “When tubefeeding was first discussed, I didn’t like the idea and didn’t want to have surgery. However, I spoke with another girl who had CF and got a G-tube and it didn’t seem so bad. I also was tired of people telling me I had to eat.

“A lot of people don’t like the thought of a G-tube ‘button’ always being present. I only have to hide it when I put on a bikini bathing suit. I cover it with a band-aid, but most of the time, I just casually place my hand over it when walking around. In regular clothes, it never shows. If a band-aid’s over it, and people ask, I just say I scraped my belly. Most of the time, people don’t really see it. And if I’m tanning and people stare, I really don’t care. It’s really not that big of a deal. My good friends know it’s there and don’t care. Besides, I’m not the center of the universe.

“G-tube feeding is definitely worth it. I started to look anorexic before I got it. I put on weight immediately and felt better and stronger. When I start to get sick, my appetite is the first thing to go. The G-tube gives you extra ‘insurance’

for when you get sick. You have a few pounds to play with. I feel much better in the morning when I have my feed the night before. Doing my night feeds gives me the extra calories I need when I just don’t feel like eating. Tubefeeding has given me a general boost in growth and an overall confidence in how I look and feel.”



Maggie, age 8, at Children’s Memorial Hospital with dad Ed and brother Steven.

From Maggie's mother: "When the CF team suggested tubefeeding, at first I thought they were 'crazy'. My kid wasn't that 'sick'. But as I watched her growth chart at each visit look worse and worse, I realized I wasn't doing her any favors by not considering it. Besides, my husband and I were tired of constantly badgering her to eat when she just really couldn't.

"Beforehand, I did a lot of reading and questioning of other families who had a child with a G-tube. These are the people who are doing it day in and day out. The more I learned, the more I was able to educate Maggie about the potential benefits and why it was really only going to help her in the long run. The more positive we were about it, the more accepting she became of the idea. It has helped her so much. It takes the pressure off of her (and us). It's no big deal anymore. She looks better and feels better.

"My advice to other parents is that living with CF is much like a roller coaster ride. You have your highs and lows. Enjoy the highs and endure the lows. Having an IV pole, pump and bag for G-tubefeeding in my daughter's bedroom that first night was a real slap in the face. Now it's just another place for her to hang her clothes! Don't let CF consume you...of course it's always there, some days more than others, but try to see past it and enjoy life. Don't sit around waiting for the cure...life is passing you by while you do."



Immediately after Maggie received the G-tube, she put on weight and felt better and stronger.



Maggie's MIC-key™ tube measures 1 ½ " x ¼ " x ¼ ". Some tubes are even flatter.

An adult's view of G-tubes

Veronica is 23 years old and has had a G-tube since she was 14. She offers her advice on tubefeeding for adults with CF.

“I was 12 years old when the CF team first brought tube feedings to my attention. I was open and willing to try anything. I hated being skinny and was having a hard time gaining weight at home. Up until then, my CF team wanted me to eat three meals a day along with high calorie shakes and snacks. I hated the fact that no matter how much I ate or how high in calories it was, I couldn't gain weight. At times I hated food and eating. The CF team first introduced me to NG feedings, which I attempted twice, but both unsuccessfully.



Veronica at age 14 (above with her sister Cynthia) decided on her own to get the G-tube. After three months, she gained 20 pounds and her energy and appetite returned.

“Two years later, I was still struggling with my weight. I didn't have much of an appetite and didn't feel hungry. I had come to a point where I couldn't take it anymore. I was sick of doctors and my parents telling me to eat more. I was sick of adding to my meals to make them higher in calories when many times I just wanted to eat them plain. I was 14 years old and I knew myself well enough to know that over time I wasn't going to do the NG feedings. I was given all the information I needed about the G-tube and had decided on my own to get it. Once fully recovered from the surgery, I knew that having the G-tube would be a lot easier. No need to worry about putting the NG tube in every night and taking it out every morning and no more gagging. The G-tube would always be there and would be a constant reminder to do my feedings.

“The G-tube has completely changed my life for the better. It has helped in so many ways, not only gaining weight but gaining self-esteem and energy. At 14 years of age, I was at my lowest weight ever—72 pounds. After getting the G-tube, I gained 20 pounds in three months. I realized the G-tube was really working for me. Three months after my surgery, we got pictures of my sister's graduation and I'll never

forget how happy and shocked I was. I didn't recognize myself in the pictures. I was no longer skinny. Even though the numbers on the scale were getting higher and higher, the picture was the added bonus that the G-tube feedings were really working. I gained a lot of self-esteem after that.

“Also, after getting the G-tube, I had an appetite and felt hungry again. I actually wanted to eat and I liked it. I would do my feedings Monday through Friday and took the weekends off. The feedings gave me enough energy to go to school and hang out and keep up with my friends. For the last five years, I have been eating well enough that I am no longer dependent on the G-tube feedings. In the beginning, I used four cans at night, five nights a week. Now I only use three cans a night and three to four times a week. My G-tube feeding is used more to maintain my weight.

“Nighttime tubefeeding adds to CF care when you're busy with work or school, but I think it is worth it. Whether you're busy with work or school, you should always make time for your health. Personally, I don't think it is a lot of work. I don't see tubefeedings as adding another layer to CF, just expanding the nutritional part of CF.

“My advice for other adults with CF who are struggling with their weight is to consider all your options, ask questions and talk to others who do tubefeedings. I wouldn't suggest getting the G-tube without trying other options

first, but I highly recommend it. I'm really happy with how everything turned out. I wanted a change and was ready to do whatever I had to do to make my health better. If I accepted the G-tube and was accepting of myself, then people close to me (friends, family, boyfriends) would be accepting as well.

“I think body image is a big obstacle for some adults who consider G-tube feedings. You have to determine which is more important: how you look or your health. With whatever you choose, there is always some obstacle you have to face.

“After I got my G-tube, the one obstacle I remembered facing was changing for gym class. It worked well just to change quickly. Throughout my four years in high school with my G-tube, I never heard a word about it. The G-tube doesn't restrict me. I still go out with my friends, travel, and in the summer I go to the pool and wear a swimming suit. The activities I do are the same, if not more. I just have more energy to do them.”

After tubefeeding, Veronica gained over 50 pounds and now uses the G-tube three to four nights per week to maintain her weight.



Advice on tubefeeding

Frequently asked questions...

How and when do you give tubefeedings?

The most common methods of tubefeeding are overnight feeding and daytime bolus feeding. If you eat well during the day, but just not enough to gain weight, you would benefit most from overnight feeding. By starting the tubefeeding at bedtime, you could receive around 1500-2500 calories while you sleep. A bolus feeding involves giving a portion of tubefeeding formula through the tube during the daytime while awake. This is generally recommended for individuals (usually young children) whose voluntary food intake is too small to satisfy hunger. Boluses can be given right after eating, between meals, during a nap or even at school.

Will I still be hungry?

If you do overnight tubefeeding, you probably won't be hungry for breakfast, but your appetite will return mid-morning. Remember to continue to eat well during the daytime and evening. Tubefeeding is meant to supplement, not replace, your usual food calories. Sometimes in instances of chronic undernutrition, the appetite improves after tubefeeding is started.

How will I take enzymes for overnight tubefeeding?

There are several different approaches to giving enzymes with tubefeeding, and your CF team will guide you. It is common to give a meal dose

of enzymes at the time of hook-up, and sometimes a snack dose of enzymes when you disconnect in the morning. For children who can't swallow pills, the enzyme beads or a powdered enzyme product may be given by syringe through the tube.

How quickly will I gain weight?

In general, most individuals start at a low tubefeeding volume and advance (often within a week) to the goal set by the CF dietitian. Tubefeeding advancement is determined by how you feel—fullness, nausea, abdominal pain or diarrhea might require an adjustment in your regimen. Once you are at your goal tubefeeding volume, you should notice weight gain in the first several weeks. Initial weight gain is often substantial and tapers off as you reach your weight gain goal.

What tubefeeding formula should I use?

Selecting the right tubefeeding formula is very important because pancreatic insufficiency limits the body's ability to digest fats and proteins properly. Formulas that contain medium chain triglycerides (MCT), a specialized form of fat which is readily absorbed, are generally well-tolerated by individuals with CF. Some formulas have up to 500 calories per 8 ounces, which allows you to get more calories in less volume. If you have food allergies or other medical

conditions that affect diet, you may need a specialized formula. Your CF dietitian will recommend a formula that is best suited to your needs.

Where can I get the formula?

If you pay out-of-pocket for formula, you should shop around for the best price. Wholesale warehouse stores may be an option. Medical supply companies will generally charge less than retail drug stores. Your CF dietitian will be able to help.

Will my insurance pay for tubefeeding costs?

Most insurance policies will pay for the cost of the G-tube surgery, pump, IV pole, NG tubes and supplies. However, many insurance companies will not pay for the cost of the tubefeeding formula. Verify your individual insurance coverage prior to starting tubefeeding. If formula is not a covered benefit, talk to your CF team about additional resources.

What do I do about sleepovers and vacations?

Many individuals can skip tubefeeding for sleepovers or short trips, particularly if they have been gaining weight well. However, some people who skip their tubefeeding don't feel as energetic the next day. If you plan to do tubefeeding while staying at a hotel, you don't necessarily have to bring your IV pole.

A lamp above the bed or curtain rod, for instance, may allow you to hang the bag with creative use of a coat hanger.



While inserting the NG tube, Kyle takes a series of drinks through a straw.



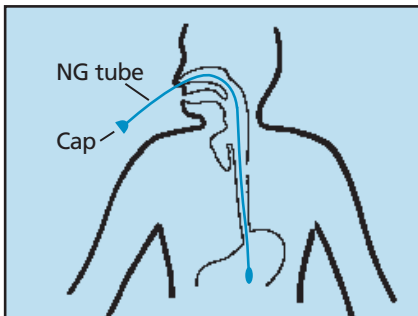
Kyle prepares his tubefeeding set up.

Advice on tubefeeding

Specific tips to make tubefeeding easier...

NG tube insertion tips for the novice

Inserting the NG tube for the first time is always uncomfortable, but rest assured it gets easier each time. A nurse will teach you the technique. Relax and take your time.



Learning the path the tube will pass will be helpful.

The following tips should make the process easier. Refer also to the detailed instructions provided by your caregiver.

1. Selecting the right tube is imperative. Ask your nurse to recommend a tube that is soft and pliable, such as an Argyle® Indwell® Feeding Tube (Sherwood Medical.) You may want to use a spray such as Chloraseptic® to numb your throat.
2. Your nurse will help you measure and mark the section of the tube that should be at your nose when the tube is fully inserted.
3. Place the tube in warm water to soften it.
4. Apply a lubricant to the tip and first inch of the tube.
5. Place the tip into your nose, advance it upward. As it approaches the curve (approximately two inches into your nose), angle it toward the back of your head.
6. Once the tip is by the throat, take a series of drinks through a straw while advancing the tube (see photo, page 13). Swallowing will help the tube move downward. Sometimes, advancing the tube quickly helps.
7. Continue to advance the tube to the marked point.
8. Test for proper positioning as instructed by your caregiver.
9. Tape the tube on your cheek to prevent it from moving out of place. Tegaderm® is recommended if your skin becomes irritated from the tape.
10. Relax and allow the tube to remain in place for as long as possible. It will become more comfortable each time you insert it.
11. When doing daily NG feedings, alternate using the right and left side of your nose.

Gastrostomy tube tips

G-tube placement surgery requires a short stay in the hospital. Your surgeon will answer any questions that you have. Our families add:

- There is some pain after the surgery, but each day gets easier. If possible, try to get up the first day.
- To reduce the discomfort when laughing or coughing, hold a pillow close to your abdomen and apply pressure.
- Keep an extra GT kit at home. G-tubes occasionally fall out and need to be replaced. Most parents/patients can replace it themselves, while others visit the surgeon or surgical nurse.

Your CF team will advise you on airway clearance right after surgery. It is common to hold off on airway clearance for the first 24 hours. Start with gentle BD or PEP therapy until you can resume your regular routine. If you use The Vest™ system, there is a dense foam block available to protect the G-tube site once healed, or ask about the chest wall vest which is designed to fit above the G-tube site.

Getting started

Plan an area (bedroom perhaps) for the tube-feeding equipment which will be delivered to your house. This will include: IV pole on wheels, enteral pump (requiring an electrical outlet), and supplies such as feeding bags, tape, etc. Keep supplies in a small wheeled cart or basket. Daily bedtime medications and/or home IV supplies can be kept here as well.

A home care nurse will teach you how to set up your pump, bag and tubing. Tape the tubing connections to avoid accidental leaks. Fold the ends of the tape onto itself, and wrap this tape around the connection. (Making “tabs” on both ends of the tape makes removal easier). Protect carpeting because formula spills can be difficult to clean. Use a water-proof mattress pad in case there is a formula leak during the night. To keep the tubing out of the way of young children, bring the tubing around to the child’s back, fold tape back upon itself over the tubing and use a safety pin to secure the tape (and tubing) to the back of his/her clothes.

Cleaning your tube-feeding supplies

Your CF team or home care company will have recommendations on cleaning your tube-feeding supplies. Some individuals use a new bag every day while others clean and reuse it several times. Because it is difficult to clean, extra care should be taken to follow the instructions given to you. To clean the G-tube extension tubing, add a teaspoon of dishwasher detergent to hot water, draw it up in a 35cc syringe and push it through. Clamp and close the extension tube openings and let it sit for a while. Flush thoroughly with abundant amounts of hot water. Alternatively, use a silver-colored pipe cleaner (such as used in art projects.) Don’t forget to bring your extension tubing to the hospital if you are admitted to avoid ordering a new kit each time.

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Children's Memorial would like to thank Digestive Care, Inc., makers of PANCRECARB® (pancrelipase), the only bicarbonate-buffered, delayed-release capsules, for generously sponsoring the printing of this guide.