



*Information and support for families of  
children with Hydranencephaly*

## Hydranencephaly Newsletter December 2008

This is our monthly newsletter about Hydranencephaly and the issues a child with Hydranencephaly might face. . Its purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group, which is hosted by Yahoo groups.

### Topic of the Month

Tube Feeding: Questions and Answers

Due to the number of questions that people have asked regarding tube feeding, the format of this newsletter is different. The table of contents will consist of a list of the questions and will be linked directly to that question. It is hoped that this is a document which will help you as you care for your child whether or not he or she has a new tube, or has had one for a long time. The information was gathered from several website, a book on Home Tube feeding by our local hospital and from my experience. Please note that this is just for reference purposes. Please always check with your child's feeding team before trying anything new.

### Table of Contents

1. [Why would my child need a feeding tube?](#)
2. [Isn't a feeding tube "unnatural"?](#)
3. [Is a feeding tube an extraordinary life saving measure?](#)
4. [What is tube feeding?](#)
5. [Will people be able to see the tube?](#)
6. [What are the different ways tube feeding can be done \(ie: does all food go in to the stomach\)?](#)
7. [How is a feeding tube inserted?](#)
8. [What is a PEG tube and how is that different to a button?](#)
9. [What type of button gastrostomy tubes are there?](#)
10. [What can I expect in hospital - e.g. pain, bleeding, how to care for it etc?](#)
11. [How often will it need to be changed and who does it? When will I know it needs to be changed?](#)
12. [What are the different ways to feed \(e.g. pump, bolus etc\), how will I know which way to feed my child?](#)
13. [How do I care for the tube site?](#)
14. [What are the differences between irritation around the tube and infection of the site?](#)
15. [How do I treat irritation?](#)
16. [How do I treat infection?](#)
17. [What is granulation tissue and how is it treated?](#)
18. [How many calories does my child need?](#)
19. [What do I feed my child?](#)
20. [How much liquid does my child need?](#)
21. [Will my child always need a feeding tube?](#)
22. [Can I still feed my child orally?](#)
23. [Can I put real food into the feeding tube?](#)
24. [Venting what is it? and how do you know if your child needs venting 'before' or 'after' tube feeding?](#)
25. [What does it mean to "check residuals"?](#)
26. [Can medicines be put in the tube?](#)
27. [How will I know if my child is being fed too fast?](#)
28. [What do I do if the feeding tube gets clogged?](#)
29. [What do I do if the feeding is leaking out around the tube onto the skin?](#)
30. [What do I do if the tube is pulled or falls out.](#)
31. [What position should my child be in when being tube fed?](#)
32. [What if he/she throws up or has diarrhea?](#)
33. [What is a Nissen Fundoplication?](#)
34. [Does he/she need it when he/she gets the feeding tube?](#)
35. [Can my child go swimming with a feeding tube?](#)
36. [Can my child lie on his/her stomach after getting a feeding tube?](#)
37. [How will I know if my child needs a new button?](#)
38. [How will I know if my child needs a different size button?](#)
39. [How do I change a Mickey button?](#)

### **1. Why would my child need a feeding tube?**

For children with Hydranencephaly and similar conditions there are 2 main reasons why they may need a feeding tube. They are: a. the child is aspirating (food is going into the lungs) what he/she is being fed, or b. the child is unable to take in enough nutrition in order to gain weight and remain healthy.

For a child with motor problems it takes a lot of energy to control their muscles to swallow safely. For those reasons it may take the child a long time to take in a feeding and often they use up so much energy that they've burned more calories than they've taken in.

Many of the children with hydranencephaly have problems controlling how they swallow so that food goes into their lungs instead of their stomachs. This is very dangerous and can cause pneumonia and other respiratory problems. Sometimes children show no noticeable signs of aspirating (this is called silent aspiration) yet damage is being done to their lungs. Other times it's very apparent that they're aspirating. A feeding tube can go a long way to prevent aspiration.

### **2. Isn't a feeding tube "unnatural"?**

That really depends on your definition of unnatural. I prefer to see tube feeding as one more "appliance" or technique in helping your child to have a full healthy life. If you think of it like you would putting afos (foot splints), or a stander or special seat then it doesn't seem to be as unnatural. Children with severe disabilities need many extra pieces of equipment and accommodations. A feeding tube is one more thing to help them.

### **3. Is a feeding tube an extraordinary life saving measure?**

Again, it depends on your perspective. In people with terminal illnesses where death is imminent it may be considered to not be in the best interest of that person. However, when you have a child who has the chance of a full life ahead of them and just needs help to eat enough, it doesn't seem unnatural at all. All it is is a different way of feeding a child.

### **4. What is tube feeding?**

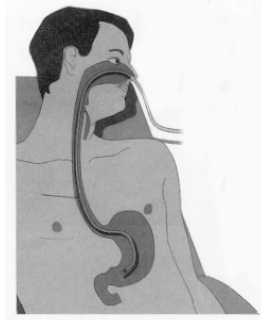
Tube feeding means that all or some of your child's nutrition will be taken via a tube that goes into either the stomach or the jejunum (intestine). There are special formulas available for tube feeding.

### **5. Will people be able to see the tube?**

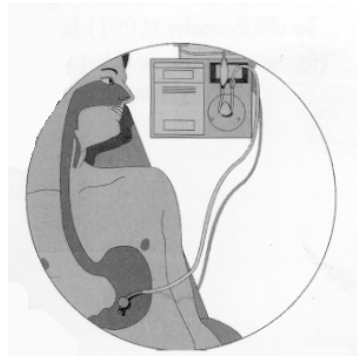
Usually no. When you're child first gets a tube it will likely be a "PEG" tube. There is about 10 inches of tubing that will be seen. However it can easily be tucked under clothing. Most children end up getting a "button" gastrostomy tube once the incision site has healed. These are quite low against the skin. You need to insert another tube into the button for feeding but again, this can be tucked under the clothes.

### **6. What are the different ways tube feeding can be done (ie; does all food go in to the stomach)?**

- There are many different routes to tube feed a child. The most common are:
- a. Naso-gastric feeding is when a tube goes through the nose, down the back of the throat and into the stomach. In some cases, the tube can go down further into the jejunum-this is called naso-jejunal feeding. This type of feeding is generally used on a short-term basis.



- b. Gastrostomy feeding is when a tube goes directly into the stomach, through a small hole (or stoma) in the abdominal wall. Sometimes people will talk about a PEG or Button gastrostomy. PEGs and buttons are types of gastrostomy tubes



- c. Jejunostomy feeding is when a tube goes into the small intestine (or jejunum), though a hole in the abdominal wall. The tube bypasses the stomach completely. (not pictured)

There are advantages and disadvantages for each type of tube:

The **nasal gastric tube** is usually used on a short term basis. As it goes into the nose and down to the stomach it is visible. It is very easy for the nasal to come out of the stomach and move into the lungs. This is very dangerous. It is also uncomfortable for the child to have a nasal gastric tube. They tend to need to be replaced fairly often. But, placing a nasal gastric tube doesn't require any surgery. A parent can be taught to place and use it quite quickly.

The **PEG or gastrostomy tube** is what is used more frequently for long term tube feeding. One disadvantage to it is that it does require a surgical procedure, although it's usually a very short surgery. Once the site has healed and your child is on a formula that they can tolerate, tube feeding can be routine and relatively problem free. For most families tube feeding is simple and just a part of life. With the use of a feeding pump a child can be fed wherever he/she is without anyone knowing about it. A gastrostomy tube can remain in the child even if it isn't needed for an extended period of time. If your child has a Mickey gastrostomy button you can be taught how to change the tube yourself at home.

The **jejunostomy tube** is used when a child can't tolerate food into the stomach due to gastroesophageal reflux (GERD). This requires a longer more invasive surgery.

However for some children it's preferable to the Nissen fundoplication surgery to cure the reflux. Before a surgical jejunostomy is done, the child will usually try out a gtube. This is where a tube is inserted through the gastrostomy site into the jejunum. Part of it will also go into the stomach. The disadvantage to this type of tube is that 2 tiny tubes run inside the one standard size tube. This makes it very easy for the tubes to get blocked. It also has to be inserted in radiology usually under a general anesthetic. However it can let you know if feeding into the jejunum will work for your child. As the intestine is smaller than the stomach, the feedings have to be administered much more slowly usually on a continuous basis around the clock.

### 7. How is a feeding tube inserted?

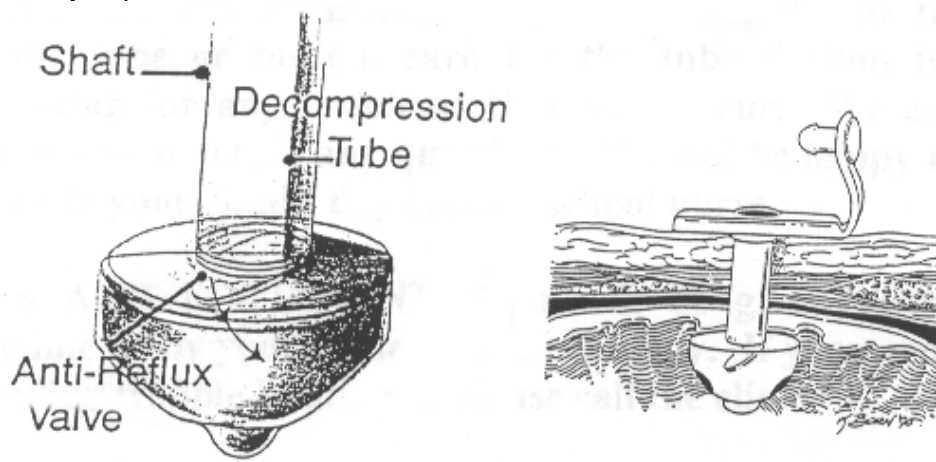
The most common way of inserting a gastrostomy tube is called a PEG which stands for Percutaneous Endoscopic Gastrostomy. In this surgery, A standard gastroscope, the type used to examine the stomach, is used to place a tube through the wall of the stomach and abdomen. On the inside of the stomach will be a balloon or "bumper" pad to hold the tube in place. On the outside you'll see a thin silicone tube coming from the opening. It is usually stitched into the skin either on the inside or outside. This is the preferred method of inserting a tube as it is less invasive than doing an open gastrostomy (the abdomen would be opened in order to place the tube). In some cases, a child will have a Nissen Fundoplication (to treat reflux) at the same time as getting a feeding tube. In that case there will be an incision. Some times the surgeon will place a "button" in the gastrostomy at the time of surgery. This really depends on the surgeon's preferences. A PEG procedure takes very little time and is much easier on the child. For more information on the actual surgery please see the November 2007 Hydranencephaly Newsletter.

### 8. What is a PEG tube and how is that different to a button?

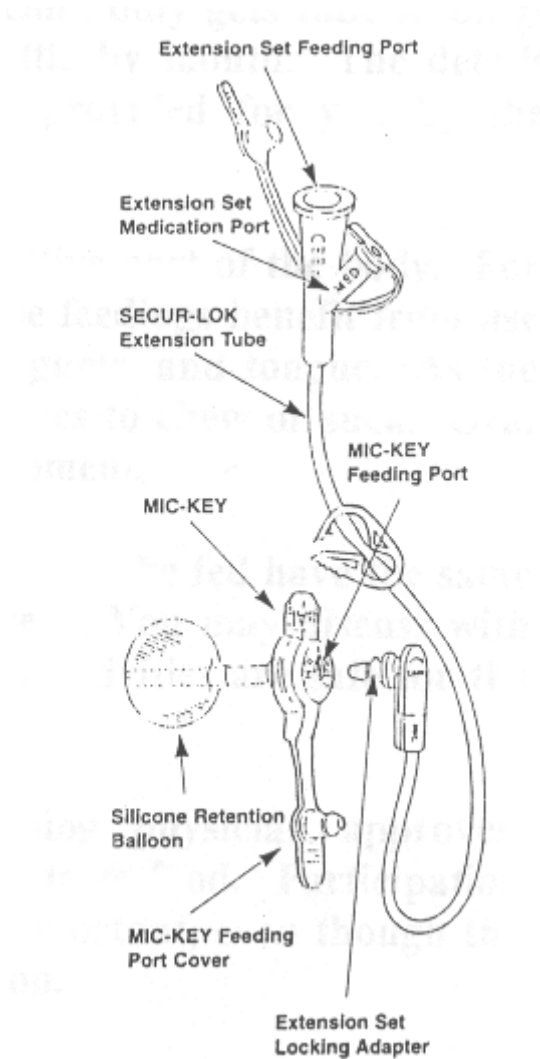
A PEG tube is simply the tube that is placed when a Percutaneous Endoscopic Gastrostomy (PEG) is performed. It is stitched to the abdominal wall. It has a bumper pad inside the stomach so it cannot be changed at home. The child will need to go back to the hospital and either have a local or general anesthetic to have another tube put in. In most cases a child will get a button gastrostomy tube (smaller and close to the skin) once the surgical site has healed. Usually about 6-8 weeks after the surgery.

### 9. What type of button gastrostomy tubes are there?

The **Bard** gastrostomy button was the first used. The advantage of it is that it's closer to the skin than some of the other buttons. The disadvantage are that the anti reflux valve that keeps food in the child's stomach tends to leak and that it can only be changed by a doctor and usually requires at least a local anesthetic.



The **MIC-KEY** button is the most commonly used gastrostomy button. The advantages are that the extension tubing (what is connected to the syringe or feeding bag) locks into the button. Another advantage is that it can be easily changed at home. The disadvantage is that it's not as close to the skin as the Bard button is. It also has trouble with the anti reflux valve leaking. It is held in place by a balloon filled with water.



The **Nutriport** Button: This is a new button and is only used by one family that we know of. It is similar to the Mickey in that it is also held in place by a water filled balloon. The family reports that it doesn't tend to leak as much as the other tubes do. This is the only picture I found.



There are a number of other buttons available. It will be up to your child's health care team to recommend which is most appropriate for your child.

**10. What can I expect in hospital - e.g. pain, bleeding, how to care for it etc?**

As a Gastrostomy requires surgery there will be some pain. But the doctors can help you make sure your child gets adequate medication to keep it to a minimum. There will be some bleeding and irritation around the surgical site. Hospital staff will help you learn how to care for the site.

Generally, children come to the hospital the day of the surgery and are admitted after the procedure is over. Most children will stay in the hospital one to two days if only a feeding tube is placed, or three to five days if both a feeding tube placement and fundoplication are done. Your child's time in the hospital will be spent recuperating from surgery and beginning feedings through the gastrostomy tube. You will be taught how to care for the gastrostomy tube and administer feedings. Arrangements will be made for home care delivery of feeding supplies.

**11. How often will it need to be changed and who does it? When will I know it needs to be changed?**

Except for the Bard button, the skin level gastrostomy tubes can usually be changed at home. The change from a PEG tube to a button is done in hospital or the doctors' office. It's usually done about 4-6 weeks after surgery once everything has healed.

A nurse can help you learn how to change the type of tube your child has.

Most tubes last about 3-6 months although the Bard is expected to last as long as 18 months. As you get used to the tube you will learn to tell when it needs changing. Sometimes it is when the anti reflux valve starts to leak. Other times the tube won't look good or the skin around it starts to break down. And sometimes the balloon will break and the tube will need to be changed right away.

Because you usually won't know ahead of time when the tube will need to be changed you should always keep a spare tube on hand. The stoma (the opening for the tube) closes quickly once the tube comes out so it is important to replace the tube quickly. If you don't have a spare tube you can put in the old one and tape it into place and then go to the hospital. If they don't have the type of tube you use a foley catheter can be inserted to keep the site open and to feed your child until you get the right tube.

**12. What are the different ways to feed (e.g. pump, bolus etc), how will I know which way to feed my child?**

**Kangaroo bag (gravity).** The kangaroo bag method uses a plastic bag connected to a long extension tube. This is simply attached to the feeding tube and liquid poured into the bag flows into the stomach by gravity.

**Bolus.** Fastest and simplest, the bolus method uses a large syringe attached to a feeding tube. The liquid is poured into the syringe and allowed to flow in as fast as is tolerated.

**Kangaroo bag (pump).** An electric pump which administers the feedings at a set rate. The pump allows feedings to be more consistent and fed at a slower rate which may help to control refluxing. Portable pumps are also available which can be hung from the back of the wheelchair so feedings can be done while on the bus, walking through a mall, or in a car etc. to allow for continuous feedings throughout the day.

The kind of liquid food to be used, the amount, and the size and number of feedings will be worked out by the physician and the dietician.

### **13. How do I care for the tube site?**

Once the site has healed it is recommended that you leave it open to the air. But all children and their sites are different. Both of my children have done better with creams and a gauze dressing kept on their site all the time. The most important thing is that anything around the tube (skin, gauze, etc) has to be kept dry. If you use gauze make sure it is replaced any time it gets wet.

Clean and check it at least twice a day. Clean around tube with plain water or saline solution. If there is redness or leakage around the tube, you can use a barrier cream such as Desitin. There is also a mixture of sulcrafate (an antacid med) and Desitin cream that can be made by a pharmacist.

If there is a lot of drainage around the tube you can apply gauze. Split gauze or "iv sponges" work well. If your child is wiggly you may need to tape the opening of the gauze to keep it around the tube.

If your child is taking a steroid of any type, including steroidal asthma medications via nebulizer, or is on antibiotics frequently yeast can grow around the tube, especially if it gets wet or moist around it. If your child is diagnosed with yeast around the tube, an antifungal cream such as Nystatin can be applied.

### **14. What are the differences between irritation around the tube and infection of the site?**

Irritation: The skin is redder than normal and "raw" looking

Any discharge is watery and clear

Skin is tender to the touch

Infection: The skin is fiery red, hot and swollen

The discharge is thick and cloudy with yellowish/green colour

Skin hurts constantly

Possible fever

Bad smell around the stoma (opening)

### **15. How do I treat irritation?**

Keep the area really clean-wash and pat dry in the usual way;

Expose it to the air-take off any dressings, pull clothing away from the stoma, pinch the ends of the bumper together and fan the skin with your hand from time to time 3 times each day.

(alternatively you can use a blow dryer set to a cool setting for 5 minutes).

Rotate the bumper/flange (what you see outside the skin)

If this treatment does not clear the skin irritation within 3 weeks, contact your doctor or nurse. The watery oozing may dry and form crusts around the stoma. You should remove these by:

1. soaking in a tub
2. cover the are with saline soaked gauze for 10 minutes. Repeat if necessary.

#### **16. How do I treat infection?**

Soak the area 4 times each day with saline soaked gauze squares.:

Wash your hands.

Use a clean bowl filled with warm saline

Open the package of the gauze by grasping it's edges and pulling them apart. Place the gauze into the bowl of saline

Lift the wet gauze into position over the stoma area. Leave it there for about 5 minutes.

Repeat this 3 times using a new gauze square each time.

Leave the skin to air dry or use a hairdryer on a cool setting to dry.

Inform your doctor about the infection. If he/she prescribes an antibiotic cream, apply it after the saline soaks. Never apply a cream unless it has been prescribed by your doctor.

#### **17. What is granulation tissue and how is it treated?**

This is a skin condition which some people find troublesome although it is harmless. In this condition a small piece of red skin tissue protrudes around the tube. It may become a nuisance if it catches on clothing or secretes a sticky yellow substance. It can sometimes be prevented by making sure that the tube is secure and doesn't move too much. I've found that putting 2 or more layers of gauze around the tube can help to a certain extent. If this is a problem for your child, see your family doctor. He may prescribe silver nitrate sticks to treat the granulation tissue.

Silver nitrate sticks are available at most pharmacies. If prescribed, you simply dip the stick in water and apply to the excess tissue. The tissue turns black and crusty and falls off. You need to repeat this daily until the skin is flat again. It is important to apply a layer of petroleum jelly around the excess tissue to protect the healthy skin before you use the silver nitrate stick. Do not touch normal, healthy skin with silver nitrate sticks as it will injure the healthy skin.

Treatment with silver nitrate sticks can be painful for the child. Another treatment that can work is to apply hydrocortisone cream around the tube and on the granulation tissue. Again, you need to consult your child's doctor before starting this treatment. My son's site is now totally clear of any irritation and granulation tissue. Previously with silver nitrate sticks, the granulation tissue would always come back within a few days of treatment.

#### **18. How many calories does my child need?**

A dietician will work with you to figure out how many calories your child needs. One thing to be aware of is that often a dietician will look at the calories needed by a typical child rather than taking into account that children with hydranencephaly don't move very much. Many of our children end up gaining a lot of weight after getting a feeding tube. It's a balance between making sure your child gets enough nutrition and seeing that they don't gain so much weight it's harder on their systems. And, sometimes, no matter how little food a child is given they still gain weight. It is important to work closely with a dietician to assess how your child is managing.

#### **19. What do I feed my child?**

Again, a dietician will tell you which formula is best for your child. It may take trying a few different formulas before finding the one that works best for your child. Many of the children have trouble handling formulas such as pediasure. They may get gurgly or congested sounding. There are quite a few formulas that are now available.

#### **20. How much liquid does my child need?**

Your child's doctor will tell you how much fluid he needs on a daily basis. They have a formula that they use. It is important that the child gets enough fluid.

**21. Will my child always need a feeding tube?**

Most children do need to continue to use their feeding tube at least some of the time throughout their lives. Some children do eat orally and then just need to get their fluids via the tube. But most of the children will use their feeding tube exclusively as they get older. One thing to keep in mind is that if your child does start eating orally and doing well taking fluids each day, you don't have to use the tube. It can just stay there for backup purposes.

**22. Can I still feed my child orally?**

That depends on whether or not your child is aspirating what is taken in orally. Your child will probably have a swallow study done to see if it is safe for him/her to eat orally. Sometimes children need to use a feeding tube all the time for awhile and can later start to eat orally. Sometimes they won't have been getting in enough calories to have the energy to swallow safely. Once they're stronger they can then start to try eating. This will need to be closely supervised by a feeding team consisting of Drs, nurses and dieticians.

**23. Can I put real food into the feeding tube?**

Although this isn't recommended by professionals, yes you can put regular food through the tube. The main risk with it is that it can clog the tube. Tubes are expensive to replace so the "experts" tend to shudder when they hear that you're feeding your child regular food. If you choose to do that it's important to mix it with enough water and to make sure the food is 100% smooth. I fed my daughter regular food through her tube for several years as she couldn't tolerate regular formulas. At first I used a syringe and pushed it in slowly. Then I figured out how to get it thin enough to run it through her pump. I used a strainer to get any residue out of the mixture first. But, it's really hard enough to get enough nutrients into the child with regular food as they often can't tolerate much volume. For that reason we eventually switched Kayda to the only food based formula which is called Compleat. She did well on that.

**24. Venting what is it? and how do you know if your child needs venting 'before' or 'after' tube feeding?**

Venting is when you put an open tube (extension tube for the Mickey buttons or a special decompression tube for a Bard button) into your child's tube and let any food or air escape. Some children, especially those who have had the Nissen fundoplication, have trouble with gas building up in their stomachs. This can be very painful and may lead to vomiting. Some children never need to be "vented" and others need it all the time. It's something that you should talk with your child's Dr. about. With your dr.'s permission, it will be a matter of trial and error as to if venting will work and what method works best. If your child sounds "gassy" or is uncomfortable you can try putting in the tube with a 60cc syringe attached. This will give room for any food to come into the syringe. If food comes out when you do this make sure it's always given back to your child.

**25. What does it mean to "check residuals"?**

Checking residuals means that you are checking to see how much food remains in your child's stomach before giving more food. Again, this is an individual need and something you should check with your child's Dr. before doing it. Some children have delayed gastric emptying so that food doesn't drain very quickly. If there is too much food left in the stomach when you start feeding him more it can lead to discomfort or vomiting. It is especially important to check residuals if your child is on a continuous feed. You need to make sure that there isn't more in the stomach than what is given in an hour. ie; if your child is fed at 80 mls./hr, you want to make sure that there isn't 80 mls. or more sitting in the stomach. If your child is getting bolus feedings (a larger amount over a short period of time) it's usually recommended that there not be more than 10% of the previous feed left in the stomach when it's time to start the next feed.

**26. Can medicines be put in the tube?**

Yes, definitely. One of the most important benefits of having a feeding tube is that it's much easier to get medication into your child. Most of the medications our children take don't taste very good. And, if your child has trouble swallowing it's often hard to make sure all goes in. The feeding tube takes care of that problem. In some cases children have been able to take less of a particular medication once they have a tube as they're now getting all of it. The only caution with giving medications via the tube is that they have to be liquid or absolutely smooth.

**27. How will I know if my child is being fed too fast?**

If your child is being fed too fast they will likely show signs of discomfort or vomit. They may also show signs of reflux such as coughing or gagging. You will come to know your child's particular signs of discomfort. If your child is being fed by a pump you may need to play around with how fast the feeding is going. If your child is bolus fed by a syringe you may also need to give him/her less at a time or over a longer period.

**28. What do I do if the feeding tube gets clogged?**

Apply gentle pressure to tube. If your child is using an extension and you aren't able to get food or medications to go in, make sure the extension tube isn't blocked. If you've ascertained that the extension tube is clear and you still can't get anything in, you can take a slip tip (thin tip) syringe filled with water and stick it directly into the button (you can do this with a Mickey button, I'm not sure about other buttons) and try to push the water through. If this doesn't work, you can try pulling back and pushing in the tube rapidly to see if this frees the blockage. If that doesn't work, try the same technique with either Coke (regular coke works best) or meat tenderizer. If none of these techniques work you will either have to put in a new tube or take your child to the dr or local hospital to have them change the tube. GJ tubes are very bad for getting blocked. Giving flushes of water every 4 hours helps to keep all tubes open.

**29. What do I do if the feeding is leaking out around the tube onto the skin?**

A small amount of clear fluid leaking from around the tube is insignificant. Check to see how much water is in the balloon that holds the tube in place (if your child has a tube with a balloon). It's generally recommended to have 5 cc of water in the balloon of a regular button. If the leaking continues you should check with a gtube nurse or practitioner for further instructions. Sometimes the child needs a longer tube or a wider tube. As what leaks out around the tube can contain stomach acid you need to take special care to protect the skin. See # 16 above.

**30. What do I do if the tube is pulled or falls out.**

This isn't an emergency but the tube needs to be replaced as quickly as possible so that the hole doesn't shrink. If you have a spare tube at home and can replace it yourself, do it. If not, you need to call your child's doctor or go to the local emergency dept.

**31. What position should my child be in when being tube fed?**

It is generally recommended that a child be sitting upright or lying on their right side with their heads and upper body raised at least 30 degrees. This is to help the food drain into and out of the stomach and can cut down on reflux and vomiting.

**32. What if he/she throws up or has diarrhea?**

Try giving formula at room temperature over a longer period of time. If condition persists, try ½ strength formula ( dilute with equal parts water) or an electrolyte solution such as pedalyte or lytren (available at a drugstore) for a maximum of 24 hours. If there is no improvement and/or condition worsens or is associated with a fever, contact doctor immediately.

**33. What is a Nissen Fundoplication?**

At the time of the gastrostomy surgery, the surgeon may recommend another surgical procedure called a fundoplication. This consists of folding the upper part of the stomach up and around the lower end of the throat (esophagus) in a little pocket as a way to control possible refluxing (vomiting) of gastric acid and food. This is a rather long, complicated procedure requiring several days of acute care. Close attention to positioning, medications and feeding schedules can be used to manage the reflux and this extensive surgical intervention is reserved for only the most extreme cases. (More information on GERD-reflux will be in the January 2009 newsletter)

**34. Does he/she need it when he/she gets the feeding tube?**

It used to be done routinely when a child got a feeding tube. Some surgeons still do. But often now, it will only be done after all other anti reflux treatments (medications, positioning and changes in formula) have failed. It can be a good surgery with great results but it can also cause a lot of problems. Again, it will be up to your child's doctor whether or not the Nissen is done and when.

**35. Can my child go swimming with a feeding tube?**

Yes, once the incision is healed and as long as there is no infection.

**36. Can my child lie on his/her stomach after getting a feeding tube?**

Yes. Just make sure that the button or tube isn't being pulled. You may want to tuck it under clothing if the tube is long enough. Some children aren't comfortable on their stomachs after getting a tube.

**37. How will I know if my child needs a new button?**

If your child is having a lot of trouble with irritation around the button, then you may want to consider changing their button. I've also found that sometimes everything looks good on the outside but my children would have pain when the button was touched or be very sensitive. When I changed the button I'd discover that it didn't look good inside and the pain went away as soon as the button was changed. You'd also have to change the button if the balloon breaks. (also covered in question 11)

**38. How will I know if my child needs a different size button?**

Your child may need a larger size button if there is a lot of leakage of stomach contents from around the button. With a Mickey button, each one is a specific diameter and length; ie; 14fr (diameter), 2.5cm (length). Sometimes leakage is caused by the diameter being too narrow and other times it can be caused by the length of the post being too long or too short. Only a doctor or a nurse will be able to tell you if the size of your child's button needs to be changed. Another indicator that the button is too small is if it is really tight against the skin or is really loose and sticking out a lot from the skin.

**39. How do I change a Mickey button?**

It is important that a nurse or doctor train you how to change your child's button. In some areas of the world, parents aren't allowed to change the buttons at home. Having said that, I will include a brief explanation of the steps involved in changing a button for your reference.

You will need:

- a. new tube kit
- b. 10 cc water or saline
- c. 10 cc syringe
- d. Water soluble gel

Steps to take:

- a. wash your hands
- b. open kit
- c. remove tube and 5 cc syringe

- d. fill syringe with 5 cc water or saline
- e. slip it into the balloon port of the tube and slowly fill balloon watching to see if there are any leaks.
- f. Allow balloon to deflate. Leave syringe with water/saline attached to the balloon port
- g. Put end of button in sterile water soluble gel
- h. Take 10 cc syringe and withdraw water from balloon of old tube
- i. Once the balloon is deflated, pull out old tube and put in new tube
- j. Inflate balloon with water/saline which is in the 5 cc syringe
- k. Clean area

There may be some bleeding from around the tube. It is important to replace tube quickly so that the hole doesn't shrink.

December Birthdays

Emily Tusing: 12/1/02  
 Kaylee: 12/1/05  
 Layla: 12/1/05  
 Mason: 12/3/01  
 Trevor: 12/24/01  
 Chrissy: 12/26/00  
 Brendan: 12/27/97  
 Ethan: 12/28/00  
 Cassie: 12/31/96

December Sadaversaries (Birthdays and anniversary dates for those who have died)

Tanner: 3/8/00-**12/101**  
 JD: **12/1/99**-3/13/03  
 Emma: 4/8/06-**12/1/06**  
 Kayda: **12/2/88**-6/23/00  
 Kirsten Fielder: 3/13/91-**12/2/05**  
 Rebekah: 8/8/03-**12/303**  
 Angelina: 10/5/05-**12/4/05**  
 Aiden: 10/12/04-**12/5/04**  
 Michael: 9/12/95-**12/5/02**  
 Daniel: **12/7/95**-1/9/05  
 Brianna: 1/22/03-**12/8/03**  
 Lara: 2/23/06-**12/10/06**  
 Emily: 1/18/99-**12/11/07**  
 Preston: **12/13/99**-1/22/07  
 Katie: **12/20/85**-3/20/04  
 Isaiah: **12/22/97**-10/17/04  
 Dameon: 6/24/02-**12/30/03**  
 Matthew Pace: 5/24/00-**12/30/02**



As 2008 draws to a close, I wish all of you a very special Christmas and a Happy New Year.

Topic for next month's newsletter: Gastroesophageal Reflux (GERD) and it's treatment