


























Feeding Tube Information

Compiled by: Perry Binet

Disclaimer: I am not a nurse or medical professional. None of the information below should be used in lieu of medical advice from a medical professional. I am merely sharing information that I have learned and picked up while on the feeding tube journey with 2 of my boys. I am sure there are different ways of doing things as well as a lot more information that I do not know about. Here's what I've learned... I hope you find it helpful. (My friend, a pediatric nurse, reviewed all the information for accuracy.)

Feeding Tube Glossary:

				
Balloon	Bolus	Briefcase	Button/peg	Clamp
				
Clog	Error	Extension/ connector	Feeding bag	Feeding port
				
Flush	Gravity	LOVE	Meds port	NPO
				
Plunger	Pole	Prime	Pump	Site
				
Split gauze	Sterile	Syringe	Tube	Vent

About Feeding Tubes:

Feeding tubes are a Bracha. Brachos come in many different forms. It can also be quite scary to trudge down this path and to come to the realization that your child is joining the ranks of children with feeding tubes. Know that a feeding tube placement does not need to be a permanent solution. For the time being, lots of stress can be eliminated knowing route of getting your child to eat, the reason may be for the tube. to mean that your child is that have feeding tubes for a kids that use it just for



that there is an alternate hold food down, or whatever Feeding tubes also do not need critically ill. There are children myriad of reasons, including medication, sick care

management, back up if the child does not eat and that cannot be an option for whatever underlying reason, supplemental nutrition, nighttime nutrition, fluids, and more. Speak to your doctor and decide together if this is the right step for your child. If it is, welcome aboard! It looks a lot scarier than it really is, is way cooler than it looks, and is also way, way more helpful than you can imagine! Bless the tube.

2 Common Types of Feeding Tubes:

❖ **NG Tube/Nasal Gastric Tube**-Tube through the nose

- This is usually more temporary
- Tube can be placed by a medical professional or anyone trained (A scan will usually be needed the first time to make sure the placement of the tube is ok-not too deep, in the correct place, etc.)



❖ **G Tube/Gastric Tube**-Tube through the stomach

- This is usually more permanent but it does not mean it will be lifelong
- A hole in the stomach needs to be made surgically before the tube is placed



Both the NG and G tubes can be used with feeding pumps. NG tubes should not be used with gravity feeds, just with a pump.

Feed types will be discussed later.

NG Tubes:

A nasogastric tube is a temporary solution to get nutrition, fluids, or medication into a child's body. It is a tube that goes into the nose and reaches the stomach. It is easy to go in which means it is also easy for it to come out. Parents are generally trained how to put the tube back in. It is fairly simple and can totally be learned. You really need to know what you are doing, though, as there is a possibility of the tube going into the lungs. Training is simple but it still needs to be learned. Below are some tips to help put the tube back in:



- Be prepared for it to come out wherever you are and have the replacement tube or a way to get the original tube cleaned handy.
- Be sure to have a stethoscope and small syringe with you.
- It is easier to put back in when the baby/child is sitting upright towards you versus laying.
- The NG tube comes with a metal guided wire that goes inside the NG tube. It makes the tube sturdier so that it can be inserted. The tube cannot go back in without this metal wire as it is too floppy. Do not discard after using as you will likely need it again.
- Using a tube with measurements on it and marking the tube with which number needs to stay at the nasal opening helps you know exactly how deep the tube needs to go in versus using a blank tube and not knowing how deep to go. It also allows you to see as soon as the tube moved but is not out yet and you can usually easily just push it back in without the stethoscope and screams drama.
- Ask to be trained to use the stethoscope and the small syringe to push in air and the air sounds will tell you if the tube is in the right place. You can also ask to be trained in the stomach juice and syringe method as well. Simple training in both of these together and knowing the measurement of the tube should give you the information you need to ace through this.
- You may need to use sensitive tape to tape the tube on the cheeks as many children break out from the tape. If the cheeks are badly irritated, discuss alternating different cheeks and nasal openings.
- Be prepared for people to stare and pity you and your child. It comes from a place of true caring. (The biggest joke in our family was that our kids were the "cutest" when they had their NG tubes. People constantly stopped us to comment how adorable they were. The minute they got g-tubes (different



times but same experience) and it was not visible, they must have lost their cuteness because all the comments stopped.)

G Tubes:

A gastrostomy tube is tube that is placed through the abdomen wall directly into the stomach which allows nutrition to go straight in. An extension gets attached to the "button" with a feeding bag (for feeding pump) or syringe filled with nutrition at its end.



There is a balloon on the other side of the tube that is filled with water (different balloons require different amounts of water) which keeps the tube in place. Meaning, think of a deflated balloon going into the stomach, add water, the balloon gets blown up, now the balloon cannot come through the hole since it is blown up and is secured. It is as simple as that. Cool, huh?

When it comes out, it often means that there was not enough water in the balloon, or the balloon burst, amongst other reasons. Otherwise, besides for if there was a big yank, it generally does not just come out on its own if there is sufficient water. Different tubes need different amounts of water. It usually says on the opening of the tube. Often, when the tube is loose, it means that there is not enough water in the balloon since water does evaporate over time. The best way to know is to come prepared with two different small syringes-one empty and one with the amount of water the balloon requires. Suck out the water with the empty syringe and see how much water is missing. Then, use the fresh syringe filled with water and fill up the balloon. Some tubes can have a little more water if it is still loose. Most doctors say that sterile water should be used (no tap or saline as the salt can disintegrate the balloon). The same protocol is done if the tube comes out. You first place the tube back in and then add the water in the balloon. If the balloon popped, it will not feel secure. If there is concern about a popped/broken balloon, check it when it is out of the stomach.

Always have a spare tube! The hole closes up fast. For some kids, the half hour mark can mean it has started to close up. For some kids the stoma closes at 3 hours. If the hole is fully closed up, another surgery is necessary. Therefore, always make sure to have a spare tube. If there is no spare tube and

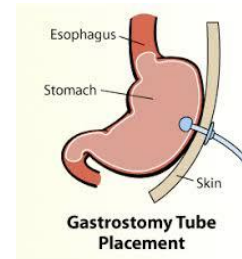


the original button is broken, put it back in and tape it down-just to keep the hole open.

Any leakage should be discussed with the doctor, as well as any new developments or changes at the site. Sometimes, when leakage crops up out of nowhere, it may be time for the tube to be resized.

Common G-Tube Types:

- ❖ **G tube**-to stomach (Most popular type)
Common Brands: MIC-KEY, MINI/MiniONE, Bard
- ❖ **J tube**-to small intestine (only continuous feeds)
- ❖ **GJ tube**-two ports: one to the stomach and one to the small intestine



Different tubes work for different children. Discuss pros and cons with your doctor about each. A pro for one child can be a con for another.

For example, if we compare the G tube to the J tube:

G:

- Goes to stomach
- Easy to put back in
- Can handle continuous (slow) feeds and gravity feeds

J:

- Goes to small intestine
- Needs interventional radiology to put back in
- Handles feeds just via a pump on a slower pace-no gravity since the feed goes in too quickly
- Minimizes vomiting since it bypasses the stomach

For a child that has a vomiting problem, a doctor may opt for the J tube and might be a solution. Each case is different.

However, since meds cannot go into a J tube because the small intestine does not absorb medication, just the stomach, meds go into the G port. This is where a GJ tube would come in handy-for a child with a vomiting problem that also needs medications.

Another example, if we compare 2 different types of g-tubes-the Bard and Minnie tubes (in reference to a specific child's needs):

Bard:

- Pro: Sleek and flat & hard for child to pull out himself
- Con: If it comes out, you cannot put it back yourself & extension does not lock

Minnie/Mic-key:

- Pros: Extension locks & can easily put in yourself
- Cons: Easier for child to pull out but bulkier than Bard

For a child that easily pulls tubes out and for a child that moves a lot and has the extension constantly disconnecting from the tube, it may be a simple decision to opt for the Minnie.

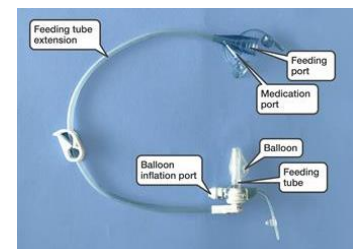
Venting:

Venting is needed in some children to release gas or built up pressure in the stomach. An empty syringe gets connected to the extension which is connected to the button. Excess juice and bubble come out. This can make the child feel better if the gas caused the discomfort.

Ports:

An extension has 2 ports-one is usually for feeds and one for meds.

- ❖ Meds port-small port on extension
- ❖ Feeding port-larger port on extension



The feeding tube button has 2 ports-one for the extension and one for the balloon. (A GJ tube has 3 ports.)

- ❖ Button port in the center-to connect the extension
 - ❖ Balloon port on side-tiny port on the side of the tube that fits the tip of a small syringe to fill the balloon with water.
- Do NOT ever put feeds straight into the button or balloon port. Always use an extension as the "go between" the syringe/feeding bag and the button.

Site Care:

- ❖ Every site looks different and different sites and skin types need different care. Some kids wear split gauzes around the site to help with leakage, and some do not. There are reusable split gauze and non-reusable. Some sites need creams like bacitracin, calmoseptine, and others, while some need powders. Some sites will have redness, infections and puss, leakage, or even granulation tissue-extra tissue that grows. Other will not. There are different medical protocols to keep the site clean and healthy. What works for one may not work for another. Please discuss with your doctor.



Feed Types:

- ❖ **Continuous feed-Pump:**
Child is constantly connected to the pump and getting small amounts of the feed, continuously (can have small breaks as directed)
- ❖ **Interval/intermittent/bolus feed-Pump:**
Child is connected to the pump (at specific times,) for a specific amount of the feed, and is usually disconnected after a feed
- ❖ **Gravity/bolus feed-Large syringe with feed inside:**
Child gets a feed through a large syringe held up at the pace of gravity and refilled until the feed is completed
- ❖ **Syringe feed-Large syringe with plunger:** (Not common as typical feed, yes common as meds)
Child gets a feed squirted into the extension through a syringe and pushed down with the plunger



Steps When Feeding:

Some people use a different order, but see below for basic general steps. It is possible that a different order or method will work better for you and that is perfectly okay.

- ❖ **Pump** (There are a few different types of pumps.)
Need:
 - Ready feed (formula prepared as directed)

- Charged pump
- Compatible feeding bag (Ex: kangaroo pump needs a kangaroo bag)
- Extension

1. Prepare feed
2. Mix well
3. Pour into bag
4. Connect bag to pump/load set
5. Set pump-most important
 - ✓ Rate
 - ✓ Volume



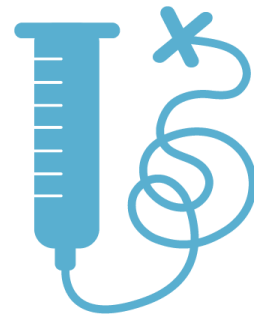
6. Prime bag (This is when the feed goes through all the tubing so that when the pump starts the feed goes straight into the stomach instead of just air if the tubing would still be empty.)
7. Make sure primed extension is connected to button-black lines should meet and then turn
8. Attach bag to extension
9. Unclamp extension
10. Make sure nothing is blocking the flow (pants/skirt, etc.)
11. Start feed

❖ Gravity/bolus

Need:

- Ready feed (formula prepared as directed)
- Large syringe (Usually 60cc/ml) and plunger (Good idea to have extra one handy)
- Syringe filled with water-if flushing is necessary
- Extension
 1. Prime extension
 2. Connect extension to button-black lines should meet and then turn
 3. Connect large syringe to extension
 4. Unclamp extension
 5. Pour in part of feed into large syringe
 6. Refill as necessary (before air goes into syringe)
 7. Clamp extension when feed is done
 8. Flush with water if required (Some children require bottled water or distilled water vs tap water)

9. Turn extension
10. Remove extension
11. Close tube
12. Wipe anything that spilled onto skin



Troubleshooting:

Sometimes the pump may act up for no rhyme or reason. Good luck!

- Sometimes the bag is not good
- Sometimes there are air bubble stuck anywhere in the tubing
- Sometimes re-priming it can help

Otherwise, different small issues may come up. If the feed is not going down, the following can be tried:

- Check if extension is unclamped
- Check if extension is bent
- Check if pants or anything else is pushing on extension too much
- Give a little plunge with the plunger to push feed
- Try to turn button softly
- If it is still not going even after that and with the plunger, take out the extension and flush with water
- If it is still clogged, attach a large syringe at end of the extension (other side) and push water through-this always works
- If all else fails, take a new extension and prime with water before
- If feed does not go down with new extension, the balloon is most likely clogged. Using coke, flush through balloon
- If nothing is working, use new tube

You will likely need to make each mistake and experience each mishap at least once. But those are going to teach you more.

Syringes:

- ❖ Syringe types:
 - Small syringes-(5 or 10 cc/ml) usually for meds
 - Large syringes (usually 60cc/ml)-for feeds



- Bulb irrigation syringe-another type of syringe that is generally used for babies. It is gentler on the stomach than the regular syringe.



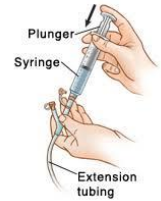
❖ Tips:

Different tips are compatible for different extensions

- Catheter tip-common
- Luer lock

Ways to get content (ex: water for flushing) into the syringe:

- Pour into syringe while the other hand has one finger at the bottom so liquid does not come out-This is good when getting water straight out of the faucet
- Pour into cup first and suck/pull up content from cup using the plunger-the part of the syringe that you push/pull



Misc Pointers:

- This is a basic overview for feeding tubes, not an official medical training. It is based on one mother's experience.
- Just be mindful that lots of parent-child bonding happens when a mother feeds her child. If this is being replaced by tube feeds, you can still bond in other ways.
- Ask people that have been there before if you have any trouble. You are most likely not the first person to experience the trouble you are experiencing.
- Get creative with your google searches. There are lots of helpful tools and items available. (To be discussed later)
- Shabbos: Make sure to charge the pump at night so that it is charged during the day. Many Rabbonim permit doing everything necessary on Shabbos with a shinoy. Follow your Rav's psak.
- If you are experiencing lots of stress in regards to getting your feeding tube supplies, switch vendors.

Helpful Feeding Tube Items:

- Tubie Friends-These are teddy bears that can be ordered with tube ports and other medical equipment. Tubiefriends.com
- Syringe feed holder-This is a holder for the syringe as the child gets a feed. It also comes with bag holders. Freearmcare.com
- Extension cleaners-These are thin and narrow brushes that can clean extensions. (Pipe cleaners can work too!) Available on Amazon-search "straw brush skinny cleaner".



- Uni-solve wipes-These are wipes that remove tape marks from the skin in a simple and non painful manner.



- Feeding tube belt covers-These are belts that cover the site/tube/extension, etc. These are 2 companies that sell good ones and there are cheaper alternative solutions from Amazon as well. For sensitive skin, I would recommend the one from Gus gear. Gusgear.com or Benik.com



If a belt is not an option, the "tubular elastic net" can be tried for babies/kids that need it covered. A small piece is snipped off from a roll and placed over the stomach. It is available on Amazon.



- Grip lock-This is an added sticker that helps secure the extension/tubing etc. to avoid it being tugged and pulled. It can also be used to secure NG tubes. It is available on Amazon. (Tape can work fine as well.)



- AMT feeding tube connector-This is an added piece that connects the bag tubing to the extension to avoid disconnection. Vitalitymedical.com



- Connector protector-This covers the clamps and avoids it opening and closing. It is available on Etsy as "custom made feeding tube".



- There are many different style feeding tube briefcases that the child or caregiver can wear. For babies, there are poles and other things to connect the pump on.



- Tubesies-These are onesies with a special flap/pocket to access the tube. Tubesies.com



- Large regular onesies-These are larger regular onesies that are helpful to keep the tube in place. Iwearmari@gmail.com

Helpful Feeding Tube Tips:

- It is worth purchasing one extra tube in the beginning so that you have 2 spare tubes in addition to the one the child is wearing (one purchased and one from insurance). When you have 1 tube as a spare and use it, you are suddenly left with none until the replacement comes and you may land up in a real emergency situation. Aiming to always have 2 spare tubes (except for when you use the first spare and wait for that replacement) has literally helped us avoid real emergencies with tubes coming out
- Coke, seltzer, diet gingerale, or any carbonated soda is miraculous for unclogging tubes and extensions (GJ/J usually required clog zapper)
- A shoe rack is a great way to keep all the little odds and ends organized
- A hanger is great at hanging up the feeding bag
- When the extension is clogged, it usually works better to syringe water through the back end (with the closure open)
- Never underestimate the power of a short little prayer when you are dealing with clogs and messes
- It's a good idea to have a "to go bag" in your car with all supplies you may need when out so that you don't need to start packing everything up if you are running out.
- Hang in there! You got this!



Life's Humor

By: Perry Binet

Each day we learn something new,
Including a new vocabulary, too!
Pegs can be good therapy toys,
Or a way to eat for some girls and boys,
When some think of gravity they think something about space,
When we think of gravity it's his feeding pace,
When some see a pump they think of a possible parking spot,
When we see a pump we think of the great tool we've got,
When some people need air they go near a vent on the wall,
To us, 'vent', is a 'get rid of air' call,
Some people have a button on clothing they wear,
While he has a button on his stomach so bare,
To some, mickey, is an entertainer so great,
To others it's the blessed tube that we so appreciate,
When most people are connected it's probably to wifi or the internet,
When he is connected it's to his feeding set,
If some people would see a kangaroo they'd run,
While our family would not leave without a precious one,
Some run to an outlet to shop for cheap things,
Our family runs to an outlet to charge the pump when it rings,
A plunger is a handy item in a bathroom,
But it's way handier to push formula down so it can zoom,
When some have a feed error they probably ate the wrong food,
While we get a feed error whenever the pump is in the mood,
To some an extension gets plugged into a wire,
To us it's part of his feeding attire,
A pole is something kids like to slide down,
To him it allowed him to crawl around town,
To some, prime, is some kind of math concept or whatever,
For him it's an action to remember forever,
When most kids are off they think about vacation,
When he is off we think about a lethargic situation,
To some, a drain, is something that can clog,
To us it's the feeding bag and then it looks like fog,
For feeding time most people get a fork, spoon, or knife,
To us it's syringes-what a blessing in life...



So you see life is awesome and strange,
And even the meaning of the most regular words seems to change,
Yet nothing in the world can redefine the love so sweet,
Between a parent and child, no matter how or what they need to eat!

Perry Binet, MS Ed, has been in the field of Special Education for 15 years. She is currently the Director of Camp Migdal, an overnight sleep-away camp for children with special needs, likes to dabble with creative, meaningful projects on the side, and most importantly, is the mother of 3 boys, 2 of which have a rare metabolic liver disease, Glycogen Storage Disease (and have tubies). She can be reached at perrybinet@gmail.com.