katefarms®

Caring for Your Tube-Fed Child at Home

PEDIATRICIAN RECOMMENDED #1 PLANT-BASED BRAND*

A comprehensive guide to support and empower you every step of the way

*Among surveyed doctors recommending plant-based nutrition products

Dear Parents and Caregivers,

Rayah

If you are reading this, it means that someone you love is beginning their journey with a feeding tube.

At Kate Farms, **our mission is to make nutrition the foundation of human well-being** so that all people can live their best lives and be all they are capable of. We understand that food, nutrition, and mealtimes are integral to our physiological, psychological, and social well-being. The transition to tube feeding can evoke a range of emotions, including relief, fear, uncertainty, and even a sense of isolation.

Your healthcare team, Kate Farms, and hundreds of thousands of others who feed through a tube or care for a person feeding through a tube are on the journey with you. While feeding through a tube is different than what you may have expected, it is also the truest gift of **nourishment, connection, and care.** It is one that you will share with your little one.

Know that you are not alone. You have resources and a community supporting you. Mealtimes with a feeding tube will continue to be an expression of love and a shared experience filled with connection and care.

With our love and support,

katefarms®

This guide provides basic information and does not replace the advice of a healthcare professional. Follow any instructions provided by your healthcare provider and contact your healthcare team with any questions about your child's tube feeding.

Contents

All videos can be found at youtube.com/@cynthiareddicktalkstubefeeding

aspen® American Society for Parenteral and Enteral Nutrition

This guide has undergone review and approval by the American Society for Parenteral and Enteral Nutrition (ASPEN).

Introduction to Tubie Life

Every child is different. There are many types of formulas, feeding tubes, and feeding methods available to fit your child's lifestyle and nutrition needs. Together, you and your healthcare team can determine the best plan for your family.

Tube feeding delivers nutrition, water, and medications in a special way that bypasses the mouth and goes straight into the stomach or small intestine. Tube feeding (aka enteral nutrition) may be prescribed for many different reasons, including for any child who has trouble swallowing, gaining weight, or meeting nutrition and fluid needs by mouth alone.

A feeding tube is one helpful tool in the toolbox to help your child thrive.

tubie ['too-bee]

noun

1. a child who is fed through a feeding tube

Hunter

"My son Hunter became feeding tube dependent at 16 months old and started gaining weight. He's thriving now."

— Sierra, Hunter's mom

Tube feeding can be challenging at the start, and it's normal to feel overwhelmed. However, with a little help and structure, we know you can rise above challenges that may come your way. Here are six tips to help set you up **for success** as you navigate this new feeding journey.

Caleb

6 Tips for New Tubie Parents

1. **Make tube feeding work for your child.** You should feel empowered to find a tube feeding practice that works for your child. Talk to your healthcare team anytime about adjusting the feeding plan if needed. You know your child best, and you play a critical role in determining what's working and what's not. The formula, feeding method, schedule, or even the type of tube your child uses can be changed.

2. **Connect with others.** Being a new tubie parent may feel overwhelming, but it does get easier. Remember that you're not alone! Look to page 34 for support resources and ways to connect with other parents and caregivers.

3. **Arm yourself with knowledge.** Don't be afraid to ask questions. There are many options out there to consider. The more you know, the more empowered you will feel. Start with some basic information about types of formulas and tubes on pages 9-14.

4. **Stay organized.** Record your child's treatment plan and type of feeding on the next page. Use the Notes page at the end of this guide to write down questions for your healthcare team.

5. **Keep things easy.** See page 34 for some helpful tools to make feeding easier and maybe even a little fun, like child-sized pump backpacks, kid-friendly G-tube pads, and clothing designed for easy access to the tube.

6. **Give yourself grace.** Tubie life can be a significant adjustment for the whole family. Most days won't be perfect and that's okay! Set realistic expectations for yourself, celebrate the small victories, and give yourself grace as you discover this new territory.

Your Child's Tube Feeding Plan

Use this space to write down your child's feeding plan and tube type.
Ask your healthcare team if you are unsure about anything.

Feeding Plan

Date: _____

Formula Name: _____

Total Per Day: _____ container(s) (_____ mL/_____ oz) to provide _____ calories

Feeding Method and Schedule

☐ Syringe ☐ Gravity Bag ☐ Reusable Pouch

____ container(s) (____ mL/____ oz) delivered over ____ minutes or ____ hours ____ times per day

Other: _____

☐ Pump

____ container(s) (____ mL/____ oz) delivered over ____ minutes or ____ hours ____ times per day

Other: _____

Water Flushes

____ mL ____ times per day and ____ mL before and after each feeding or medication

Total Water Per Day: _____ (____ mL/____ oz)

Other Additions (e.g., modular products, vitamins recommended by the healthcare team, etc.)

_____

_____

_____

mL = milliliter(s)
oz = ounce(s)

Your Child's Tube Feeding Plan (Continued)

Feeding Tube Information

Manufacturer: _____

Length: _____ French Size (Fr): _____

Tube Type

- ☐ Nasogastric (NG)
- ☐ Nasojejunal (NJ)
- ☐ Gastrojejunostomy (GJ)
- ☐ Gastrostomy (G)
- ☐ Jejunostomy (J)
- ☐ Other: _____

[ ] Standard Profile [ ] Low Profile [ ] Balloon [ ] Non-Balloon/Bumper/Bolster

[ ] Other: _____

Use: ☐ Feeding ☐ Medication ☐ Draining ☐ Venting ☐ Other: _____

ENFit®: ☐ Yes ☐ No

Download and fill out the wallet-sized Feeding Tube Information Card from The Oley Foundation (oley.org). Keep it handy to share with healthcare providers when traveling or for medical visits.

Exploring Options

“Our son, Hank, was diagnosed with congenital CMV and generalized polymicrogyria when he was 6 [months] old. We have always struggled with feeding issues, which means we also have problems gaining weight … Hank had a G-tube placed and is back to living his best life well fed!”

— Samantha, Hank’s mom

Hank

Exploring Options
Enteral Formulas

It is important to remember that there are many types of enteral formulas available. If one is not working for your child, there are other options you and your healthcare team can explore. If your child is not able to tolerate their recommended daily amount of formula, let your healthcare team know as soon as possible. Below are some common characteristics of enteral formulas.

Calorie Concentration

Pediatric formulas for ages 1 and up are available in different calorie concentrations: less than 1.0, 1.0, 1.2, and 1.5 calories per milliliter. A higher calorie concentration means more calories per container. Your healthcare provider may recommend a lower or higher calorie concentration, depending on your child's calorie and fluid needs. You might also use a formula with a higher calorie concentration to reduce feeding time or volume, while still meeting your child's nutrition needs.

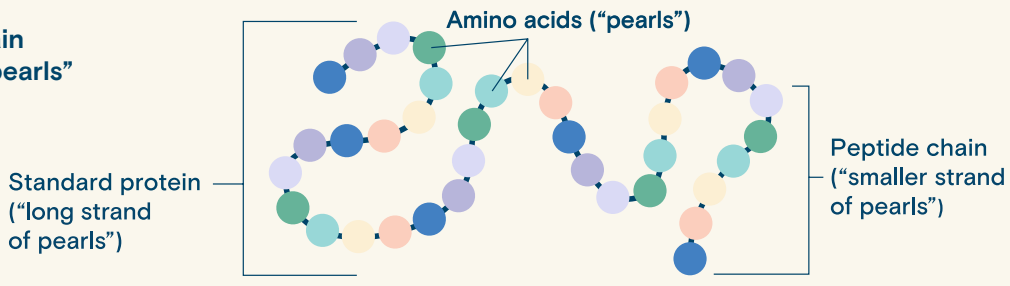
Example: 240 mL of a formula that has 1.0 calories/mL provides 240 calories (240 x 1.0). The same amount of a 1.5 calorie/mL formula provides 360 calories (240 x 1.5).

Protein Type

Protein helps repair and build cells and is important for growth and development. Enteral formulas contain protein in various forms (intact, hydrolyzed, or elemental). It might help to think about these different forms as parts of a pearl necklace.

Intact Protein Formula (aka standard formula)	The protein has not been broken down — it remains a "long strand of pearls." This type of formula would be used if digestion and absorption are intact.
Hydrolyzed Formula (aka peptide formula)	The protein is partially broken down (partially hydrolyzed) into smaller chains, or a "smaller strand of pearls." This type of formula is sometimes recommended if digestion or absorption is impaired, or if an intact/standard formula is not tolerated.
Elemental Formula (aka amino acid-based formula)	The protein is completely broken down into its simplest form: individual amino acids, or "pearls." This type of formula may be recommended if a peptide formula is not tolerated.

Figure 1.
Protein chain "strand of pearls"



Enteral Formulas

Protein Source

The protein in enteral formulas typically comes from either animal-based sources, such as milk (sometimes listed in the ingredients as casein or whey), or plant-based sources, such as pea or soy. Food allergies or intolerance to milk or soy may play a role in which formula you and your healthcare team decide on.

Fiber Content

Fiber is important to support normal bowel function. Some medical conditions may require reduced fiber intake. Talk to your healthcare team if your child's formula does not contain fiber.

Taste

The way a formula tastes and smells is important, even if your child is not drinking it by mouth. They may "taste" the formula while burping it up or smell it when you open the container.

Blended Formulas (aka Blenderized)

Blended formulas provide a way to include more whole foods in your child's diet. Some people also use them to help with symptoms of intolerance if conventional formulas are not well tolerated. They can be used alone or combined with other types of formula.

Commercially prepared blended formulas are available with intact or hydrolyzed protein. Whether you're making blends at home or using a commercial blended formula, be sure to work with your healthcare provider to make sure your child's nutrition needs are met.

Feeding Tubes

Just like there are many different types of formulas, there are many different types of feeding tubes. Your child may start with one type and change to another type of tube later, depending on your child's unique needs.

For more information about your child's specific tube, a manual from the tube manufacturer may be available from your healthcare team, home care company, or online.

Where the Tube Starts and Ends

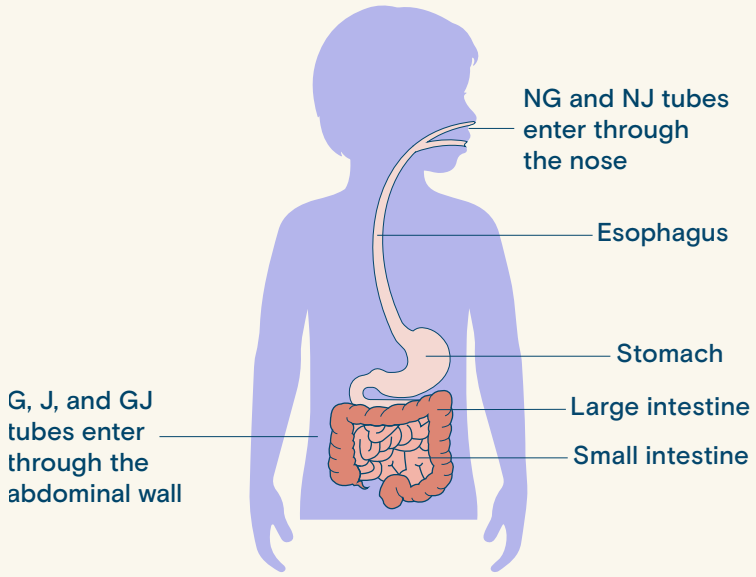
For short-term use (usually a few weeks, up to 2-3 months), a feeding tube can be inserted through the nose and down into the stomach or small intestine. For longer-term use, a hole called a stoma is created in the abdominal wall for the tube to enter directly into the stomach or small intestine.

Formula, water, and medications delivered into the tube end up in the part of the gastrointestinal (GI) tract where the tip of the tube ends. The tip of the tube can end in either the stomach, the small intestine, or both.

Stomach	• Nasogastric (NG) tube • Gastrostomy (G) tube
Small intestine	• Nasojejunal (NJ) tube • Jejunostomy (J) tube
Stomach and small intestine	• Gastrojejunostomy (GJ) tubes are a little different because they have a tip in the stomach and in the small intestine. This makes it possible to feed formula into the small intestine and drain or vent stomach contents if the stomach is not working well.

Figure 2.

The gastrointestinal (GI) tract

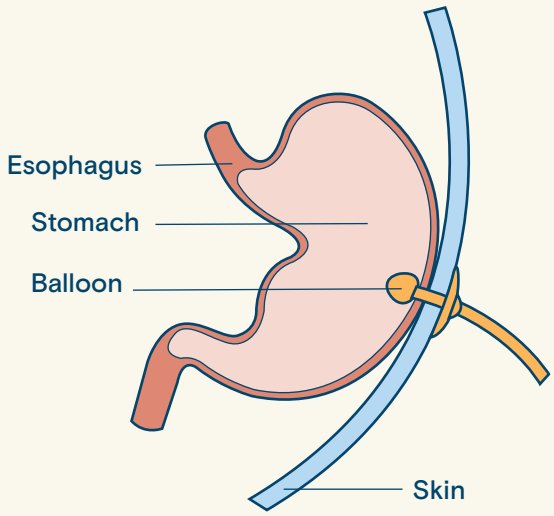


Feeding Tubes

Keeping the Tube in Place

A tube inserted through the nose is kept in place with tape or an anchoring device. A tube placed through the abdominal wall is held in place inside the abdominal wall by either an internal bolster or a balloon that holds water (Figure 3). If the tube has a balloon, it will have a port to fill the balloon with water. Balloon tubes are easier to insert and remove but may need to be replaced more often than tubes with an internal bolster.

Figure 3.
G-tube held in place with a balloon

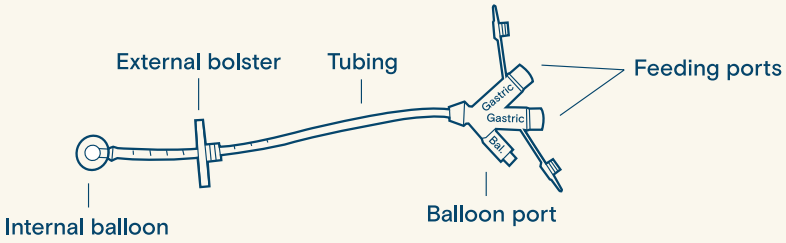


French (Fr) size describes the outer diameter of the feeding tube. Larger diameter tubes may accommodate thicker liquids, such as homemade blenderized formula.

Feeding Tubes

Tube Types

Figure 4.
Standard profile G-tube with balloon

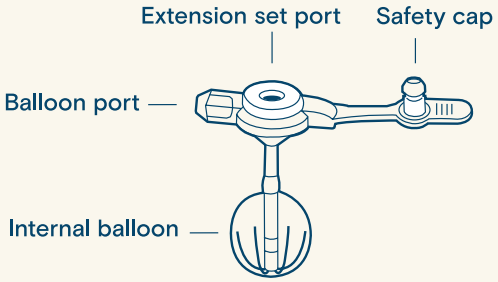


A standard profile tube (aka dangler) has tubing that extends outside of the abdominal wall. An external bolster keeps the tube in place.

The tube can have one port for feeding and may have additional ports for medications and for filling the balloon.

Keep dangling tubing away from little hands by pinning it to clothing or using a device called a G-tube belt.

Figure 5.
Low-profile G-tube with balloon



A low-profile tube (aka button) sits close to the skin and requires extension tubing, called an extension set, to deliver formula, water, and medications. Extension sets are available for bolus and continuous (pump) feeding. This type of tube is commonly used in children to prevent little hands from grabbing at dangling tubing while the tube is not in use.

Figure 6.
Extension set (bolus)

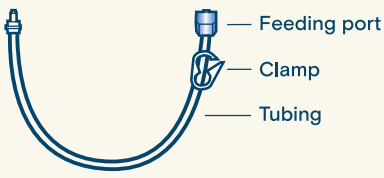
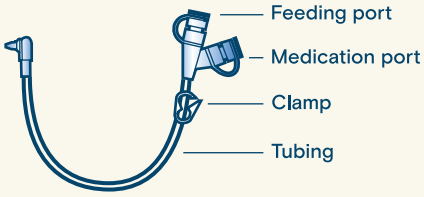


Figure 7.
Extension set (continuous)



Extension Set Types Video

Feeding Tubes

ENFit® Connections

It's important to know which type of connection your child's feeding tube has. This way, your home care company or healthcare provider can provide the right type of supplies that work with the tube.

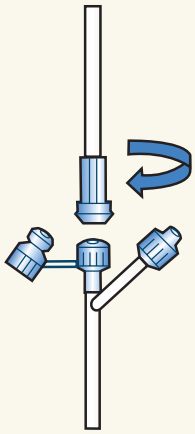


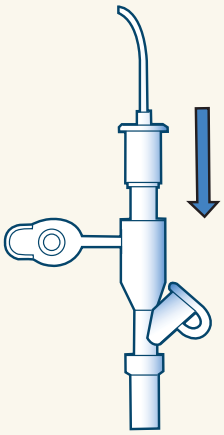
Figure 8.
ENFit connection

Feeding tubes, gravity feeding sets, feeding pump sets, and enteral syringes with ENFit connectors have a special twisting design that does not fit with non-feeding devices; they only fit with other feeding devices that also have ENFit.

ENFit connectors were designed to help prevent tubing misconnections, which can happen when feeding devices are accidentally connected to non-feeding devices, such as IV lines or ventilator tubing.

Figure 9.
Legacy connection

Feeding devices without ENFit (legacy devices) have an end that looks more like a funnel. They can fit with many other types of devices they were not intended for.



Legacy vs. ENFit Syringe Connections Video

Be sure to fill out your child's feeding tube information on page 7, including whether it has an ENFit or a legacy connection.

Getting Ready to Feed

“Born with multiple esophageal and tracheal abnormalities and heart defects, our son’s journey to health has been quite the ride. He was unable to take in anything by mouth for the first 14 months of his life. No matter what we did, he couldn’t clear 15 pounds … I finally asked our dietitian if there is anything different we could be giving him … For the first time in his life, he is thriving.”

— Rebecca, Bond’s mom

Bond

Getting Ready to Feed
Flushing the Tube With Water

Flushing the tube with water helps keep the tube clean and your child hydrated. Read the tips below for more help.

Why?	Flushing the tube with water: • Keeps the inside of the tube clean. • Provides fluid to help keep your child hydrated. • Helps prevent a clogged feeding tube, which could stop you from being able to use the tube.
What?	Water is the best liquid for flushing. Other liquids could contribute to a clogged tube. • Tap water — This is generally fine to use in the home setting. • Bottled water — You may want to use this if you are concerned about contaminants in your tap water. • Purified water — Your healthcare team may recommend this if your child has a weakened immune system.
When?	Flush the tube before and after you put anything in it, including medicine and formula.
How much?	Your healthcare team will tell you how much water to use for flushing and how much water your child needs each day.

Supplies

- 60 mL (2 oz) enteral syringe
- Clean cup or glass
- Room temperature water or formula (the amount recommended by your healthcare team)

Instructions

1. Fill a clean cup with room temperature water.
2. Put the tip of the syringe in the water and pull back on the plunger to draw up the recommended amount.
3. Uncap or unclamp the feeding tube or extension set and attach the syringe to the feeding port.
4. Gently push on the plunger to push the water through the tube.
5. Cap or clamp the feeding tube or extension set.

Priming the Extension Set

If your child has a low-profile feeding tube (Figure 5 on page 13), prime the extension set (fill it with water or formula) before connecting it to the feeding tube.
This helps prevent air from entering the stomach or intestine and causing discomfort.

Supplies

- 60 mL (2 oz) enteral syringe
- Clean cup or glass
- Room temperature water or formula (the amount recommended by your healthcare team)

Instructions

1. Unclamp the extension set.
2. Remove the plunger from a 60 mL enteral syringe.
3. Attach the syringe to the feeding port on the extension set.
4. Pour 10 to 15 mL of formula or room temperature water into the syringe, and allow it to flow to the end of the tubing.
5. Clamp the extension set.
6. Attach the extension set to your child's feeding tube.
7. Unclamp the extension set.

Proper Positioning During Feeding

Proper positioning during feeding helps reduce the risk of aspiration, which can lead to pneumonia.
Aspiration happens when formula refluxes from the stomach, back up the esophagus and into the lungs.

During feeding and for 30 minutes after feeds:

- Sit your child upright in a chair or on the couch (Figure A).
- If your child is in bed, keep the head of the bed elevated at least 30 degrees (Figure B).

Figure A.

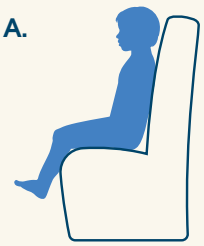
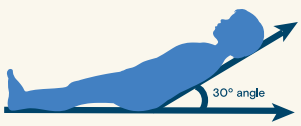


Figure B.



Is your child getting enough water? Notify your healthcare team if you notice any of these signs: increased thirst, dry lips and skin, dark or concentrated urine, or rapid weight loss.

Formula Hang Time

Hang time is the recommended amount of time a formula can be “hanging” during a feeding at room temperature. The times below are a general guide for tube feeding at home. Check with your healthcare provider or the formula manufacturer if you have any questions.

Up to 2 hours	• Home-blended formulations
Up to 4 hours	• Reconstituted formula and breast milk • When water or modulars (additional powders or liquids) are added to the formula
Up to 12 hours	• Ready-to-use formula • Commercially prepared blended formulas (or per manufacturer)
Up to 48 hours	• Closed system/ready-to-hang formula (sterile pre-filled container that connects directly to a feeding tube)

Refrigerate unused formula for up to 24 hours. Bring refrigerated formula to room temperature by placing it on a countertop for 30 minutes. Avoid heating the formula in any way.

Feeding Methods and Instructions

“Robbie is G-tube fed and relies solely on formula for nutrition … As parents, we love knowing no matter where we go, his formula is packed and ready with the vitamins and minerals he needs to thrive!”

— Kristy, Robbie’s mom

Robbie

Feeding Methods and Instructions

There are many options to choose from when it comes to how you feed your child. The feeding method you use is determined by you and your healthcare team and may depend on your child's condition and lifestyle needs.

You should feel empowered to discuss choosing a different feeding method with your healthcare team at any time. You may also combine feeding methods. For example, you might bolus feed with a syringe during the day and pump feed at night while your child is sleeping to meet their nutrition needs in a 24-hour period. Ideally, the feeding method(s) you choose should work with your family's lifestyle.

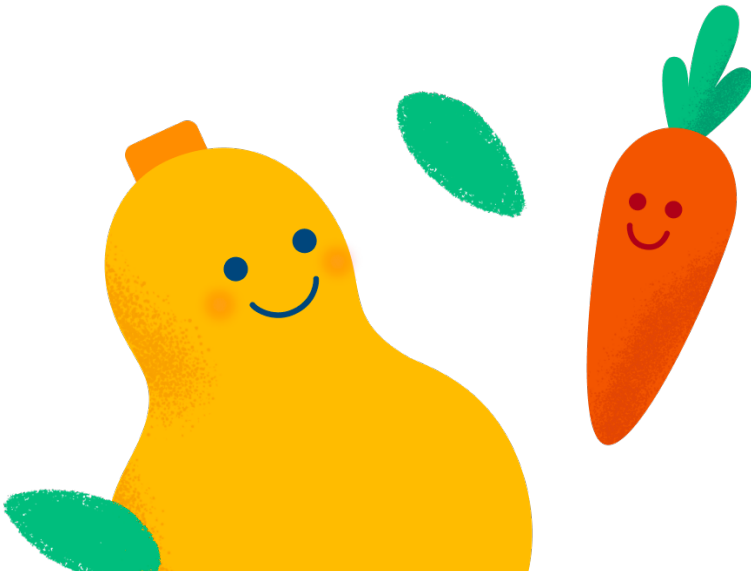
The following pages provide descriptions and general instructions for common feeding methods. Follow any instructions provided by your healthcare provider.

Feeding Tips

Keep it clean. Always wash your hands with soap and water before and after handling your child's feeding tube or supplies.

Give it a shake! If your formula container has a twist-off cap, remove the cap to break the seal, replace the cap, and shake vigorously.

Bring to room temperature. Delivering cold formula via the feeding tube may cause stomach upset. Bring refrigerated formula to room temperature by placing it on a countertop for 30 minutes. Avoid heating the formula in any way.

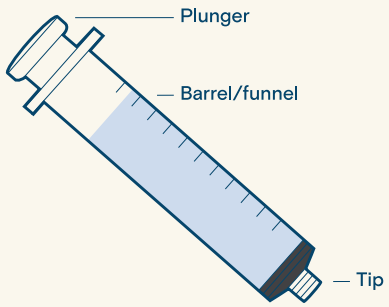


Bolus/Syringe

Bolus feeding with a syringe provides formula in a short amount of time.
It should take at least 15 minutes or longer to give your child about 240 mL (1 cup) of formula through the tube using the bolus/syringe feeding method.
You can feed with the syringe in two ways: push method and funnel/gravity method.

1. **Push method:** You can use the plunger in the syringe to push the formula through the feeding tube.

Figure 10.
60 mL enteral syringe with ENFit® connection



Supplies

- Formula
- 60 mL (2 oz) enteral syringe
- Clean cup or glass
- Room temperature water (for flushing)
- Clean cloth

Instructions: Push Method

1. Flush the feeding tube with the recommended amount of water.
2. Pour the formula into a clean cup or glass.
3. Using the syringe, pull back on the plunger to draw up the formula.
4. Attach the syringe to the feeding port on your child's tube or extension set.
5. Slowly push the plunger to give formula through the tube.
6. Repeat the steps above until the prescribed amount of formula has been given.
7. Flush the feeding tube with the recommended amount of water.
8. Disconnect the syringe, cap your child's tube, and wipe up any spilled formula.
9. If you will be reusing the syringe, rinse with warm water and allow it to air dry, or follow your healthcare provider's instructions.

Bolus/Syringe

2. **Funnel/gravity method:** You can remove the plunger and pour formula directly into the syringe, allowing formula to flow by gravity into the feeding tube. This method allows for a slower flow, so it may be better tolerated than the push method.

Supplies

- Formula
- 60 mL (2 oz) enteral syringe
- Room temperature water (for flushing)

Instructions: Funnel/Gravity Method

1. Flush the feeding tube with the recommended amount of water.
2. Remove the plunger from the syringe.
3. Attach the syringe to the feeding port on your child's tube or extension set.
4. Slowly pour the formula directly into the syringe barrel.
5. Raise or lower the syringe to speed up or slow down the flow. You can also put the plunger back into the syringe and gently push any remaining formula through.
6. Repeat the steps above until the prescribed amount of formula has been given.
7. Flush the feeding tube with the recommended amount of water.
8. Disconnect the syringe, cap your child's tube, and wipe up any spilled formula.
9. If you will be reusing the syringe, rinse with warm water and allow it to air dry, or follow your healthcare provider's instructions.

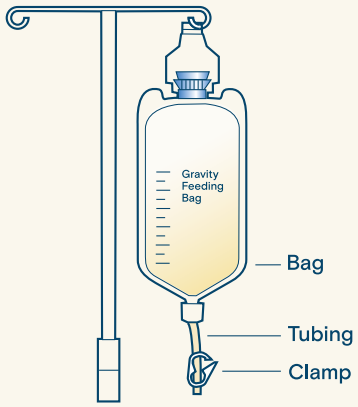
Syringe Feeding Basics Video

Gravity Bag

Feeding with a gravity bag is a hands-free way of giving formula through the tube. The bag can be hung from an IV pole or hook. The bag's tubing connects to your child's feeding tube or bolus extension set. Gravity helps the formula flow into the feeding tube. You can control how fast or slow the formula flows by hanging the bag higher or lower or by using the roller clamp.

Gravity Bag Feeding Basics Video

Figure 11.
Gravity feeding set



Supplies

- Formula
- 60 mL (2 oz) enteral syringe
- Gravity feeding set
- IV pole or hook
- Room temperature water (for flushing)
- Clean cloth

Instructions

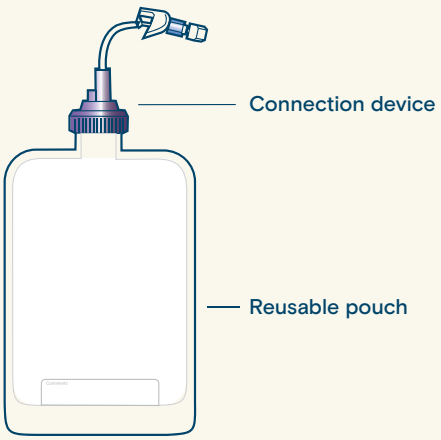
1. Flush the feeding tube with the recommended amount of water.
2. Close the roller clamp on the feeding set, pour the formula for this feeding into the gravity bag, and close the lid.
3. Hang the bag on an IV pole or hook.
4. Prime the line to remove any air from the tubing (this helps prevent air from entering your child's stomach and causing discomfort):
   a. Uncap the tubing on the gravity set.
   b. Slowly unclamp the tubing to allow the formula to flow to the very end.
   c. Re-clamp and recap the tubing to stop the flow.
5. Remove the cap and attach the gravity feeding set to the feeding port on your child's tube or extension set.
6. Adjust the roller clamp to control how fast the formula goes into your child's feeding tube. You can also raise or lower the height of the bag to speed up or slow down the flow. Let the bag empty completely. Refer to recommended formula hang times (page 18).
7. Disconnect the feeding set, cap your child's tube, and wipe up any spilled formula.
8. Flush the feeding tube with the recommended amount of water.
9. If you will be reusing the feeding set, rinse with warm water and allow it to air dry, or follow your healthcare provider's instructions.

Reusable Pouch

A reusable pouch may be used to store and deliver tube feeding nutrition and water. The reusable pouch feeding system typically includes a connection device to connect the pouch to a feeding tube or extension set.

Reusable Pouch Method Video

Figure 12.
Reusable pouch



Supplies

- Formula
- 60 mL (2 oz) enteral syringe
- Reusable pouch feeding system
- Room temperature water (for flushing)
- Clean cloth

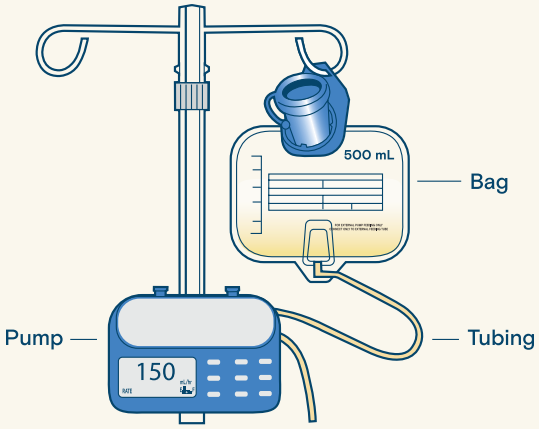
Instructions

1. Flush the feeding tube with the recommended amount of water.
2. Remove the reusable pouch cap.
3. Fill the reusable pouch with up to 375 mL (13 oz) formula or water.
4. Attach the connection device.
5. Squeeze the reusable pouch to fill the connection device tubing.
6. Clamp the tubing and attach it to the feeding port on your child's tube or extension set.
7. Unclamp the connection device and let the formula flow (squeeze the reusable pouch for faster flow).
8. When the feeding is complete, clamp the connection device and disconnect it from the feeding tube.
9. Cap your child's tube and wipe up any spilled formula.
10. Flush the feeding tube with the recommended amount of water.
11. If you will be reusing the reusable pouch, clean it with warm soapy water, rinse, and allow it to air dry, or follow your healthcare provider's instructions.

Pump

A feeding pump delivers formula at a controlled rate in milliliters (mL) per hour over a certain number of hours each day. This type of feeding may also be called continuous feeding. You can use a pump for longer feedings that take many hours, or you can use it to give the formula over a shorter time period.

Figure 13.
Enteral feeding pump set (bag with tubing)



Supplies

- Formula
- 60 mL (2 oz) enteral syringe
- Feeding pump
- Feeding set compatible with your pump
- Room temperature water (for flushing)
- IV pole, hook, or enteral backpack
- Clean cloth

Instructions

1. Flush the feeding tube with the recommended amount of water.
2. Pour the formula for this feeding into the feeding bag and close the lid securely. Hang the bag on the IV pole or hook or secure into an enteral backpack.
3. Attach the tubing on the feeding set to the pump, following the pump manufacturer's instructions.
4. Prime the tubing of the feeding set following the pump manufacturer's instructions.
5. Set the pump to desired settings following the pump manufacturer's instructions.
6. Attach the end of the tubing on the feeding set to the feeding port on your child's tube or extension set.
7. Start the feeding and let it run until the recommended amount is delivered. Refer to recommended formula hang times (page 18).
8. Disconnect the feeding set from the feeding port on your child's tube or extension set.
9. Flush the feeding tube with the recommended amount of water.
10. If you will be reusing the feeding bag, rinse with warm water and allow it to air dry, or follow your healthcare provider's instructions.

Beyond the Feeding

“Due to slow motility and emesis … we tried several different formulas for our g-tube-fed daughter … it’s allowed [her] to start eating purées while still gaining all of the nutrients from the formula that we use as a base.”

— Rome, Cali’s dad

Cali

Beyond the Feeding
Giving Medication Through the Tube

Discuss with your healthcare team which medication form is best for your child and the tube. Medications in liquid form may be less likely to clog the feeding tube.

Use the steps below as a general guide. Always follow your healthcare team's specific instructions for each of your child's medications.

Supplies

- 10-60 mL enteral syringe
- Warm water
- Clean cup or glass

Instructions

1. Prior to any medication, stop the feeding and flush the tube with the recommended amount of water.
2. Prepare the medication following the instructions of your healthcare team. This may involve dissolving a crushed tablet (or the contents of a capsule or liquid medication) in water to form a solution.
3. Put the tip of the syringe in the solution, and pull back on the plunger to draw up the solution.
4. Clamp or pinch the feeding tube or extension set, and open the feeding or medication port.
5. Attach the syringe to the feeding or medication port of your child's feeding tube or extension set and unclamp.
6. Gently push the plunger to give the medication through the tube.
7. Flush the tube with the amount of water recommended by your healthcare provider.
8. Recap the feeding tube or extension set.
9. If you will be reusing the syringe, rinse with warm water and allow it to air dry, or follow your healthcare provider's instructions.

Help prevent tube clogs! Give each medication separately from each other and from formula. Always flush with water before and after each medication.

Venting a G-Tube

Ask your child's healthcare provider if you should release air from your child's stomach by venting or "burping" the tube. Below are some general steps. Follow any instructions provided by your healthcare team.

1. Uncap and unclamp the tube.
2. Remove the plunger from a 60 mL syringe.
3. Attach the syringe to the feeding tube or extension set.
4. Try pressing gently on your child's stomach or lifting their legs to help release the air.
5. If liquid flows up into the tube, allow it to flow back into the stomach. This liquid contains important nutrients and electrolytes.
6. Recap the tube.

Formula Storage

- Store unopened formula in a cool, dry place out of direct sunlight.
- Always check the best by date before using.
- Reclose, write down the date, and store any unused formula in the refrigerator for up to 24 hours before discarding.

Oral Hygiene

Keep your child's mouth clean and moist, even if they are not taking food or liquids by mouth. This helps prevent oral bacteria from moving down the airway and causing an infection.

- Floss and brush with a soft toothbrush and toothpaste (check with your doctor first) at least once daily.
- Wipe the inside of your child's mouth with a clean, damp washcloth or mouth swab.
- Avoid alcohol-containing mouthwashes, as these can be drying.

Caring for Tubie Skin

Cleaning the skin around your child's feeding tube is an important part of your daily routine to help keep the skin healthy. It may be normal to see some drainage and crusting around the stoma site for several days after initial tube placement.

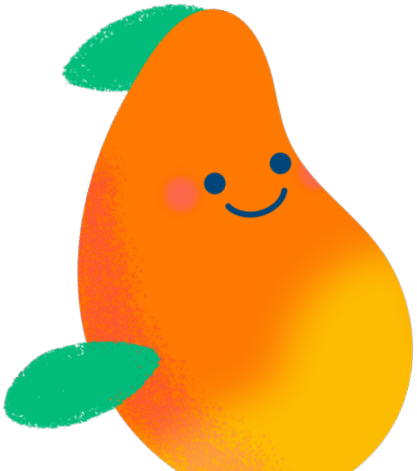
- Check the skin around the feeding tube daily. If you notice redness, pain, swelling, irritation, or leaking around the site, notify your healthcare team.
- Use only mild soap and water. Do not use anything else on the area unless directed by your healthcare team.
- Ask your healthcare provider if you should rotate the tube and how often. Do not rotate J-tubes.
- If your child's tube has an external bolster, make sure the bolster is not overly tight as this can cause skin breakdown or erosion. There should be about the thickness of a dime between the bolster and the skin.

Supplies

- Clean cloth
- Warm water

Instructions

1. Wash your hands thoroughly with soap and water.
2. Carefully remove any dressing (gauze and tape) from around the tube.
3. Using gauze or a clean, soft cloth, cleanse the skin around the tube daily with mild soap and water. This can also be done in the shower.
4. To remove any crusting around the tube site, use cotton swabs or a clean, soft cloth moistened with warm water.
5. Clean under the external bolster (Figure 4 on page 13).
6. Dry the skin around the feeding tube site thoroughly.



Overcoming Challenges

“My son was born with severe congenital heart disease and heterotaxy syndrome … [This] has been a GAME CHANGER for him and his weight and overall health!”

— Kayla, KS’s mom

Kayla’s son

Overcoming Challenges

Troubleshooting and Managing Common Problems

These are only some of the common problems a tube-fed child may experience. These basic guidelines do not replace the advice of a healthcare professional. Always contact your healthcare team with questions about your child's tube feeding.

Gastrointestinal Issues

Problem	Possible Cause	Possible Solution
Constipation	• Not enough water intake • Not enough fiber intake • Certain medications	• Ask your healthcare provider about increasing water flushes, switching to a fiber-containing formula, or changing your child's medications or supplements.
Diarrhea or watery stools	• Feeding too fast	• Slow down the feeding. Ask your healthcare provider about changing the rate or feeding method.
	• Not enough fiber intake	• Ask your healthcare team about adding supplemental fiber or switching to a fiber-containing formula.
	• Certain medications	• Review your child's medications with the healthcare team.
	• Infection or inflammation in the gastrointestinal tract	• Talk to your child's healthcare team.
Stomach upset, nausea, vomiting, or bloating	• Feeding too fast	• Slow down the feeding until your child can tolerate the prescribed rate. • Ask your healthcare team about changing the rate, feeding method, or formula.
	• Formula intolerance	• Ask your healthcare team if it is okay to relieve gas by venting or "burping" your child's tube (page 28). • Ask your healthcare team about trialing a different formula.
	• Cold formula	• Make sure formula is at room temperature.
	• Certain medications	• Review your child's medications with the healthcare team.
	• Feeding while lying flat	• During feeding and for 30 minutes after feeds, sit your child upright or elevate the head of the bed to at least 30 degrees (Figure B on page 17).

Gastrointestinal issues that don't go away are not a normal part of tube feeding and should be addressed. There are many options to discuss with your child's healthcare team, including trying a different formula or adjusting the feeding method.

Troubleshooting and Managing Common Problems

Tube Issues

Problem	Possible Cause	Possible Solution
Water or formula won't go down the tube	• Tube is clamped or kinked	• Make sure the clamp is open and inspect the tube for kinks.
	• Dried medication or formula inside the tube	• Follow instructions for resolving a clogged feeding tube (page 33).
Fluid leaking from around the tube at the stoma site	• Stem length of tube too long (low profile tube)	• Talk to your healthcare team to make sure your child's tube is the right size.
	• External bolster is too loose (standard profile tube)	• Adjust the external bolster height (there should be about the thickness of a dime between the bolster and the skin).
	• Underinflated balloon	• Inflate the balloon to the fill volume recommended by the manufacturer.
	• Stomach is too full • Too much formula or water too fast	• Slow down or decrease the volume of feedings and talk to your healthcare team.
	• For any possible cause	• Protect the skin with a short-term dressing and apply a moisture barrier if recommended by your healthcare team. • Keep the tube clamped when not in use.
The tube becomes displaced or falls out	• Deflated or ruptured balloon (if applicable)	• Replace the tube immediately. • Inflate the balloon to the fill volume recommended by the manufacturer. • If the tube will not stay in and/or the balloon will not stay inflated, keep the tube in place with cloth tape until it can be replaced with a new tube. Contact your healthcare provider immediately. The stoma can close quickly, making it more complicated to insert a new tube.

Skin Issues

Problem	Possible Cause	Possible Solution
Redness, pain, swelling, or irritation of the skin around the tube	• Tube or external bolster too tight or too loose	• Check the balloon fill volume or adjust the external bolster height.
	• Use of harsh cleansers	• Use only mild soap and water for daily cleaning.
	• Bacterial or yeast infection	• Keep the skin clean and dry. Leave the skin open to air unless your healthcare team tells you to apply a dressing. The skin around your child's feeding tube should look clean and healthy. If you notice anything different, consult your healthcare team.

Resolving a Clogged Feeding Tube

If water or formula won't go through the feeding tube, or if you notice resistance when flushing, your child's tube may be clogged. Make sure the tubing is not clamped or kinked, then follow the steps below.

To prevent a clogged feeding tube, flush the tube with water before and after each use and regularly when not in use. See instructions for flushing the tube on page 16.

Supplies

- 10-60 mL enteral syringe
- Warm water
- Clean cup or glass

Instructions

1. If you can locate the clog, massage it gently with your fingers to try and break it up (for standard profile tubes).
2. Draw up 15 mL of warm water or the amount recommended by your healthcare team.
3. Attach the syringe to the feeding tube.
4. Gently move the plunger back and forth to help loosen the clog.
5. Clamp or pinch the tube and allow the water to sit in the tube for 10 to 30 minutes to soften the clog.
6. Repeat the steps above until the clog is released.

If these steps don't work, contact your healthcare team. They may have techniques that will be more effective. Do not attempt to put any objects down the tube.

Managing and Preventing Clogged Feeding Tubes Video

Support and Resources

C.C. Moo LLC
ccmooclothing.com
Makes quality onesies and children's clothing with concealed zippers and hidden side seams to protect the tube from little hands, while allowing for discreet feeding and easy caregiver access.

FreeArm®
freearmcare.com
The portable FreeArm® Muscle holds syringes, feeding bags, or lightweight pumps and clamps to a table, wheelchair, or stroller, making hands-free and on-the-go feedings possible.

Joy by J&J
etsy.com/shop/joybyjandj
Makes tube pads, port covers, clips, and medical tape in fun designs.

The Oley Foundation
Oley.org
Provides support for home tube-fed adults and children with newsletters, a video library, online community forums, support groups, an annual consumer conference, and more.

Tubie Friends™
tubiefriends.com
Creates stuffed animals with feeding tubes and other medical devices to mirror what each child is experiencing.

U Deliver Medical
udelivermedical.com
Offers tube feeding delivery products and accessories designed to make home tube feeding easier and more patient-friendly, such as the reusable Bolee® Bag. They also make administration sets (Bolink® Large Cap, Bolink® Small Cap, and Bolink® D Cap) that connect your child's feeding tube directly to certain formula containers for convenient, no-mess feeding. The Bolee Bag and all Bolink Caps are covered by insurance if supplied by a home care company.

Support and Resources

Your Home Care Company

Keep in touch with your home care company to help ensure a smooth experience with your child's home tube feeding supplies.

Call them if:

- ☐ you have less than 14 days of supplies and are not expecting a delivery
- ☐ your child has been admitted to the hospital
- ☐ you have questions about your supplies

Call them if there is a change to:

- ☐ your child's tube feeding plan
- ☐ your address and contact information
- ☐ your emergency contact information
- ☐ your child's insurance information
- ☐ the doctor who prescribes your child's nutrition

Home Care Company _____

Phone _____

Email _____

Your Child's Care Team

It's important to feel you can trust and confide in your child's care team.
They should listen to you and be flexible enough to discuss your concerns and ideas.

Below are example members of a typical healthcare team. You may have others, such as physical therapists, speech therapists, or feeding therapists. All are an important part of your child's care team.

Doctor _____

Phone _____

Email _____

Registered Dietitian _____

Phone _____

Email _____

Nurse _____

Phone _____

Email _____

Other _____

Phone _____

Email _____

About Kate Farms®

We're here to support you

Our dedicated Customer Care Team can help you with questions about our formulas, insurance coverage, or transitioning to Kate Farms. Reach us at **katefarms.com/contactus**

Our mission is to make nutrition the foundation of health, so people can live their best lives and be all they're capable of.

Our first shake was made for Kate and her health needs. Half a million people later, we're nourishing lives everywhere as the #1 doctor-recommended plant-based brand.*

Sign up for emails and follow us on social media to join our tubie community.

We love sharing tips, resources, and more.

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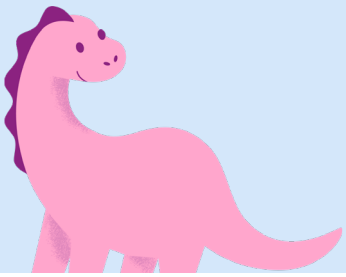

Glossary of Terms

Here are just a few of the terms that you may come across as you navigate tubie life.

Term	Definition
Bolus/Syringe Feeding	Bolus feeding with a syringe provides formula in a short amount of time. You can feed with the syringe in two ways: push method and funnel/gravity method.
Elemental Formula (aka amino acid-based formula)	In an elemental formula (aka amino acid-based formula), the protein is completely broken down into its simplest form: individual amino acids. This type of formula may be recommended if a peptide formula is not tolerated.
ENFit® Connections	Feeding devices with ENFit connectors have a special twisting design that does not fit with non-feeding devices.
Enteral Formula	Enteral formula is a special liquid food mixture containing calories and nutrients that is administered into the gastrointestinal (GI) tract through a feeding tube or by mouth.
Enteral Nutrition	Enteral nutrition refers to a way of delivering nutrition directly into the stomach or intestine through a feeding tube.
Extension Set	Extension sets attach to low profile feeding tubes to deliver formula, water, and medications into the tube or to vent air from the stomach.
Feeding Pump	A feeding pump delivers formula at a controlled rate in mL (milliliters) per hour over a certain number of hours each day. This type of feeding may also be called continuous feeding.
French Size	French size describes the outer diameter of the feeding tube. A larger size can accommodate thicker liquids.
G-Tube	A gastrostomy tube enters through the abdominal wall and ends in the stomach.
G-Tube Pads	G-tube pads are padded pieces of fabric designed to be worn under the feeding tube (between the external part of the tube and the skin), which help absorb leaks and protect the skin.
GJ-Tube	Gastrojejunostomy tubes are a little different because they have a tip in the stomach and in the small intestine. This makes it possible to feed formula into the small intestine, and drain or vent stomach contents if the stomach is not working well.

Glossary of Terms (Continued)

Term	Definition
Gravity Bag Feeding	Feeding with a gravity bag is a hands-free way of giving formula through the tube. The bag can be hung from an IV pole or hook.
Hydrolyzed Formula (aka peptide formula)	In a hydrolyzed formula (aka peptide formula), the protein is partially broken down (partially hydrolyzed) into smaller chains. This type of formula is sometimes recommended if digestion or absorption is impaired or if an intact/standard formula is not tolerated.
Intact Protein Formula (aka standard formula)	In an intact protein formula (aka standard formula), the protein has not been broken down. This type of formula is used if digestion or absorption is unimpaired.
J-Tube	A jejunostomy tube enters through the abdominal wall and ends in the jejunum, which is part of the small intestine.
Low Profile Tube	A low profile tube (aka button) sits close to the skin and requires extension tubing called an extension set to deliver formula, water, and medications.
mL	milliliter(s)
NG Tube	A nasogastric tube enters through the nose and ends in the stomach.
NJ Tube	A nasojejunal tube enters through the nose and ends in the jejunum (part of the small intestine).
oz	ounce(s)
Standard Profile Tube	Standard profile tube (aka dangler) has tubing that extends outside of the abdominal wall. An external bolster keeps the tube in place.
Tubie	A child who is fed through a feeding tube.
Venting	Ask your child's healthcare provider if you should release air from your child's stomach by venting or "burping" the tube.
Water Flushes	Flushing the tube with water keeps the inside of the tube clean, provides fluid to help keep your child hydrated, and helps prevent a clogged feeding tube, which could stop you from being able to use the tube.

Notes

Caring for Your Tube-Fed Child at Home

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katefarms.com

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*Among surveyed doctors recommending plant-based nutrition products