



PARENTS' GUIDE TO PEDIATRIC TUBE FEEDING



PARENTS' GUIDE TO PEDIATRIC TUBE FEEDING: A PERSONAL MESSAGE

If you've recently learned your child will need to be fed through a tube, it's natural to have questions. Maybe you're wondering why a feeding tube is necessary. You're unsure how much or how often to feed your child. Or you wish you felt more confident when setting up and using the equipment.

If these questions and worries sound familiar, please know you're not alone. In the United States, more than 200,000 children need home tube feeding (also called enteral feeding)—a number that is increasing as nutrition science and feeding technology advances.¹

Good nutrition will support your child's growth, general health, and optimal development. As a parent, you play an important role in providing the right nutrition for your child. Your child's healthcare team will guide you. This resource will help you begin by sharing information on:

- The “whys and hows” of tube-feeding
- The basics of getting started
- Safe routine feeding practices
- Conditions that require special guidance from your child's healthcare professionals

In this resource, we've included the best-practice guidance from leaders of the American Society for Parenteral and Enteral Nutrition (ASPEN) from their newly-published practical handbook for professionals.² Our goal is to provide you, as a parent with a guide that will lead you through this new

experience of tube-fed nutrition for your child.



1. Mundi MS, Pattinson A, McMahon MT, et al. Prevalence of home parenteral and enteral nutrition in the United States. *Nutr Clin Pract.* 2017;**32**:799-805.

2. *ASPEN Enteral Nutrition Handbook: Second Edition.* Silver Spring, MD: American Society for Parenteral and Enteral Nutrition; 2019.

	GETTING STARTED WITH HOME TUBE FEEDING	4
	TUBE FEEDING BASICS	5
	FEEDING YOUR CHILD	10
	GIVING YOUR CHILD MEDICATION THROUGH A FEEDING TUBE	16
	MANAGING AND MAINTAINING YOUR CHILD'S FEEDING TUBE AND EQUIPMENT	17
	RESOLVING ADVERSE PHYSICAL SYMPTOMS RELATED TO TUBE FEEDING	20
	NAVIGATING YOUR DOCTOR VISITS	24
	COMMUNITY SUPPORT	25
	SPECIAL CONSIDERATIONS	27
	SUMMARY	29
	APPENDIX	30



Content reviewed and approved by The American Society for Parenteral and Enteral Nutrition (ASPEN)

These recommendations do not constitute medical or other professional advice and should not be taken as such. To the extent that the information published herein may be used to assist in the care of patients, this is the result of the sole professional judgment of the attending healthcare professional whose judgment is the primary component of quality medical care. The information presented in these recommendations is not a substitute for the exercise of such judgment by the healthcare professional. Circumstances in clinical settings and patient indications may require actions different from those recommended in this document. In those cases, the judgement of the treating professional should prevail.



GETTING STARTED WITH HOME TUBE FEEDING

Good nutrition is important to your child's growth and development, both now and in the years to come. Providing the right amounts of calories, protein, fat, and essential nutrients gives your child what is needed to maintain their health. Good nutrition can also help prevent the onset of chronic diseases later in life.

WHY TUBE FEEDING?

Tube feeding may be necessary to ensure your child receives the proper amount and balance of nutrients. The essential nutrients your child needs are provided by a specialized formula given through a tube directly into the stomach or small intestine.

The length of time your child will require this feeding method is dependent upon several factors. Your healthcare team will provide further information based on your child's clinical condition. Shorter periods of tube feeding are typically associated with a major surgery or trauma, while longer periods of tube feeding are commonly associated with an illness or medical condition that limits food intake through the mouth.

Getting your child started on tube feeding can feel a bit overwhelming, but with help from your doctor and the information in this guide, you can learn the basics. The process will become easier with practice.

In this booklet, you will find: (1) general information on tube feeding, (2) instructions for managing tube feeding, and (3) strategies to help avoid common issues with tube feeding. Most importantly, this guide will help you develop a personalized plan for your child's tube feeding care. This resource contains suggested durations and timelines, as well as suggested amounts of fluid for managing your child's feeding tube. These suggestions were developed using best practice guidance from the American Society for Parenteral and Enteral Nutrition's (ASPEN) practical handbook for professionals. Your doctor will help you develop a personalized plan, which may include guidance that is best for your child.

Let's get started.



TUBE FEEDING BASICS

TUBE FEEDING FORMULAS

There are a few different types of formulas available. These formulas are available in different containers including cans, recloseable plastic bottles, tetra packs and ready-to-hang bottles. Based on your child's nutritional needs, your doctor will assist you in selecting the right type of formula and method of delivery. Your doctor will specify how much formula to give for each feeding, and how many feedings are needed each day. To help you organize this information, we created a Tube Feeding Nutrition Plan. This form can be found in the appendix at the end of this book.

THERE ARE FIVE BASIC TYPES OF TUBE FEEDING FORMULAS:

TYPE	COMPOSITION	DESCRIPTION	MEETS THE NUTRITIONAL NEEDS OF
STANDARD	Intact protein, carbohydrate, fat; vitamins and minerals	Nutrients are similar to a regular oral diet	Children with regular digestion and absorption
PEPTIDE-BASED	Protein in the form of peptides, carbohydrates and fat; vitamins and minerals	Protein is made up of amino acids When protein is digested (broken down) in the body, it is broken down into amino acids. Peptides are chains of amino acids at varying lengths, which are easier to digest and absorb	Children with malabsorption, maldigestion or other medical conditions
ELEMENTAL OR AMINO ACID-BASED	Protein in the form of amino acids, carbohydrates, and fat; vitamins and minerals	Provides protein in the form of amino acids Amino acids are the building blocks of protein. They are protein in the simplest form and are easy for the body to absorb	Children with digestive problems, food allergy, or other medical conditions.
SPECIALTY	Protein (intact, peptide or amino acid), carbohydrates, and fat; vitamins and minerals May also contain specialized ingredients such as medium chain triglycerides (MCT), structured lipids, fiber	Specialty formulas are designed for specific medical conditions by providing ingredients that may not be found in standard formulas.	Children with specific conditions
BLENDERIZED FOODS	Carbohydrates, protein, and fat; vitamins and minerals	Regular food that has been liquified in a food processor. Blenderized formulas are either prepared by the caregiver or are available as commercial real food formulas	Children with regular digestion and absorption

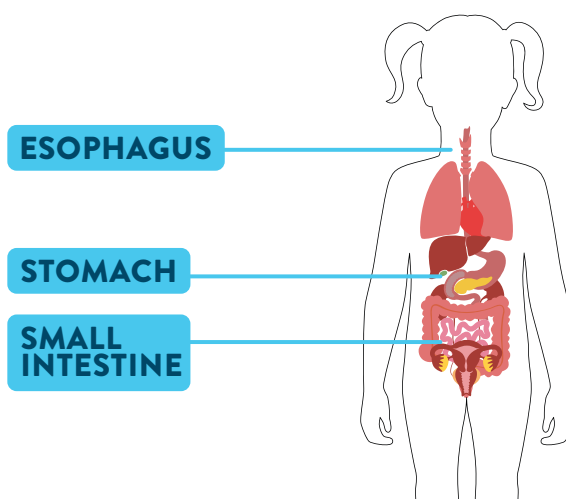


TUBE FEEDING FORMULAS

It is important to monitor how your child tolerates the formula. Use the *Tube Feeding Monitoring Checklist* (in the appendix of this booklet) to keep a record of your child's response to the formula. Share this information with your doctor during your child's routine medical visits, or when your child is experiencing any adverse reactions during feeding.



CHILD GASTROINTESTINAL ANATOMY



TYPES OF FEEDING TUBES

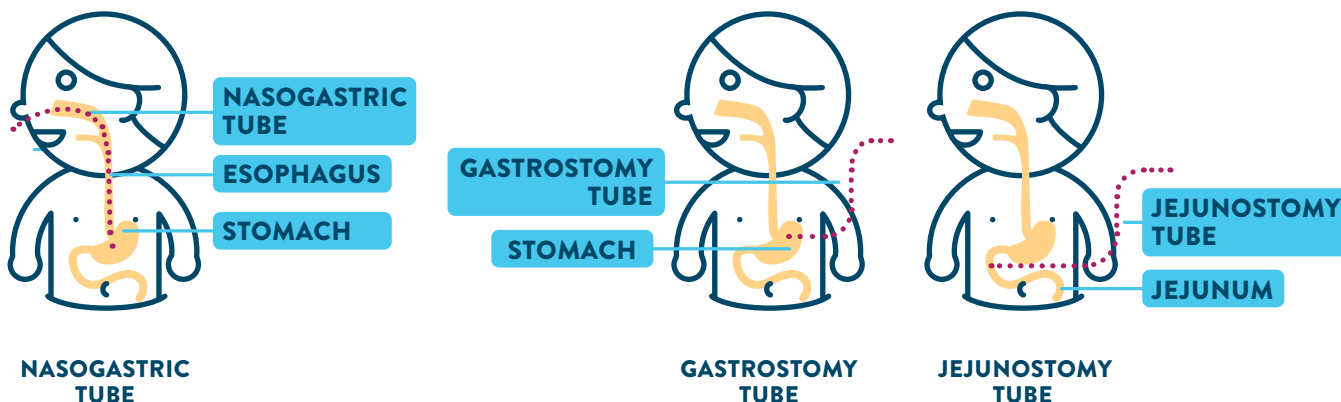
There are a few types of feeding tubes available, and your doctor will determine which one is best for your child. The type of tube your child will receive depends on the underlying medical condition, the length of time that tube feeding will be needed, and on your child's gastrointestinal tract function.

TUBE TYPE	DESCRIPTION	FEEDING SITE	INDICATION/ DURATION OF FEEDING	ADDITIONAL INFORMATION
NASOGASTRIC TUBE (NG)	Tube inserted through the nose and into the stomach	Stomach	Tube feeding of less than 4 weeks duration	NG tubes can remain safely in place for weeks or removed after each feeding
NASODUODENAL (ND) OR NASOJEJUNAL (NJ)	Tube inserted through the nose and into the small intestine (duodenum or jejunum)	Duodenum or jejunum (small intestine)	Tube feeding of less than 4 weeks duration	ND and NJ tubes can remain safely in place for weeks
GASTROSTOMY TUBE (G-TUBE)*, PEG TUBE (PERCUTANEOUS ENDOSCOPIC GASTROSTOMY) OR LOW-PROFILE DEVICE.	Tube inserted through a small incision in the abdomen	Stomach	Tube feeding greater than 4 to 6 weeks duration	Stitches may hold the tube in place until the site is healed. Once the gastrostomy site is healed, a G-tube belt, or holder is used to hold the tube in place.
JEJUNOSTOMY TUBE (J-TUBE)	Tube inserted through a small incision in the abdomen	Jejunum	Tube feeding greater than 4 to 6 weeks duration	Feedings are usually administered at a constant rate using a pump. The small intestine tolerates small volumes of feeding giving continuously.

*Your child's gastrostomy tube may need to be periodically resized and your healthcare team will discuss this process with you.



FEEDING TUBE LOCATION



FEEDING TUBE PLACEMENT

Feeding tubes have different placement methods.

- Nasogastric tube placement does not require surgery. Nasogastric tubes are inserted by clinicians or parents who have been instructed on proper nasogastric tube placement.
- Nasoduodenal (or Nasojejunal) tubes are placed by a healthcare provider, and they do not require surgery. The physician will verify correct placement.
- Gastrostomy and jejunostomy tubes are put in by a doctor during surgery or at an outpatient clinic.

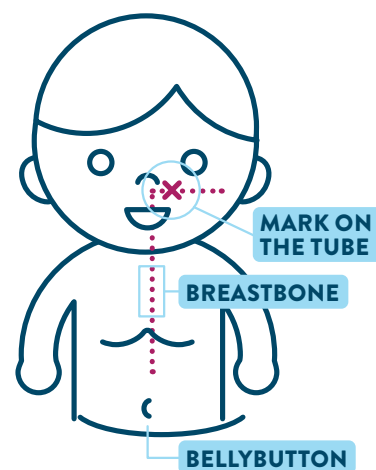
If your child has a nasogastric tube, you may be instructed on how to safely insert your child's feeding tube. Once you have been guided and instructed by your child's doctor on proper placement techniques, you can use the following reminders to help you along the way.

NASOGASTRIC TUBE INSERTION

Here is how to do it:

1. Wash your hands with soap and warm water.
2. Measure your child's nasogastric tube prior to each insertion. The end of the nasogastric tube should be placed at the tip of your child's nose and then to the ear. The tube is then extended to the spot halfway between the end of the breastbone and belly button (see figure below).

MEASURING NASOGASTRIC TUBE LENGTH





3. Mark the tube at the nose with a permanent marker. This mark tells you how far the nasogastric tube needs to be inserted.

Note: Once the nasogastric tube is in your child, the mark will let you know that the tube is in the right place. If the mark has moved, there is risk that the tube has been dislodged, and your child could aspirate (get formula into the lungs) if fed. The nasogastric tube should be removed and a new one reinserted before feeding.

4. Place your child in a comfortable position. Swaddling your child in a blanket may be comforting and provide gentle restraint. Sucking on a pacifier or sipping water through a straw for older children may help with the passage of the tube.
5. Wipe your child's cheek with a skin protectant and allow it to dry. This is the area where the tape will be applied after the nasogastric tube is inserted.
6. Place the tip of the nasogastric tube in water or a water-soluble lubricant. Some tubes have lubricant on the tip that needs to be activated with water. Check with your doctor about your child's specific feeding tube. Moistening the tip of the nasogastric tube makes it easier to insert.
7. Place the tip of the nasogastric feeding tube into the center of the nostril.
8. Gently push the tube down the nose until you reach the mark on the tube that you made with the marker. If you feel resistance, pull the tube back slightly and try to push the tube forward again.

Note: Crying, gagging and coughing is generally a normal reaction to tube placement. If your child can not breathe, remove the tube. Let your child rest before trying again to place the tube.
9. Once the nasogastric tube is in place, apply a dressing between the tube and the skin before taping the nasogastric tube to your child's cheek. The nasogastric tube should not press on the nostrils.
10. If there is excess tubing outside the nose, wind the tubing into a circle and tape it to your child's clothing to prevent the tube from being pulled out.

FEEDING METHODS

There are several methods for giving your child tube feedings: syringe, gravity, or by using a pump. The method selected for feeding is dependent on your child's clinical condition, and ability to tolerate a typical eating schedule.

Here is a summary of the feeding methods:

TYPE OF FEEDING METHOD	DELIVERY METHOD	REASON FOR USE
BOLUS	Syringe or Gravity	Mimics normal eating pattern
INTERMITTENT	Gravity or Pump	Mimics normal eating pattern
CONTINUOUS	Gravity or Pump	Gradual feeding rate for children with feeding intolerance



Bolus feedings (syringe or gravity bag)

Bolus feedings are specific volumes of food given over short periods of time. Bolus feedings are administered by filling a syringe with formula and connecting the syringe to your child's feeding tube. The feeding is given slowly over several minutes or as directed by your child's doctor. A gravity bag can also be used to infuse bolus feedings. Feedings are given several times per day.

This method is used:

- For children who can tolerate a large volume of feeding into their stomachs over a short period of time (usually less than 30 minutes)
- To mimic typical eating patterns
- To give your child more time free from tube feedings

Intermittent feedings (gravity)

Intermittent feedings are provided by using a gravity bag or feeding pump to infuse the feeding over several hours at a constant rate, several times per day. The usual infusion time is 60-90 minutes. Discuss with your healthcare provider as infusion times may vary based on your child's condition.

This method is used for:

- Children with gastrostomy tubes who are receiving feeding into their stomachs
- Children who cannot tolerate bolus feedings

Continuous feeding (pump or gravity)

Continuous feedings are administered by using an enteral feeding pump or by gravity to give the feeding at a constant rate or as prescribed by your child's physician.

This method is used for:

- Children who do not tolerate large volumes of feeding into their stomach over short periods of time
- Children receiving jejunal feedings



FEEDING YOUR CHILD

In this section, you will learn how to administer your child's tube feeding.

Before you touch your child's feeding tube or begin preparing your child's tube feeding, it is important that you wash your hands with soap and warm water. Clean your work surfaces to avoid contaminating your child's feeding and equipment with bacteria.



PROPER HAND WASHING

Checking tube placement is critical to ensuring that your child's feeding tube is in the stomach or small intestine, not in the lung, before you begin the feeding. The method for checking placement will vary depending on the type of feeding tube your child has.

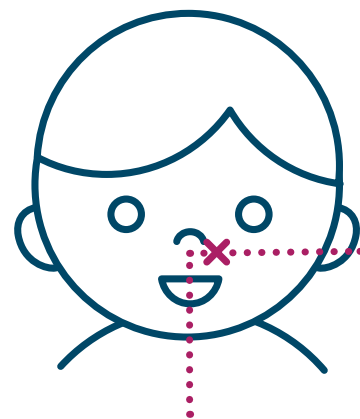
Note: If your child has a jejunostomy tube, you do not have to re-check tube placement by viewing stomach liquid before each feeding. Formula and fluid are absorbed quickly in the jejunum and do not remain in the jejunum.

CHECKING PLACEMENT OF YOUR CHILD'S NASOGASTRIC FEEDING TUBE

Here is how to do it:

1. Wash your hands with soap and warm water.
2. Find the mark on the tube that was made to measure the length of the tube from the tip of the nose to the ear and then to the mid-point between the bottom of the breastbone and the belly button.

Note: If the mark on the tube is not at the nose, the nasogastric tube will need to be removed and reinserted because the tube may have slipped out of the stomach.



CHECKING NASOGASTRIC TUBE PLACEMENT

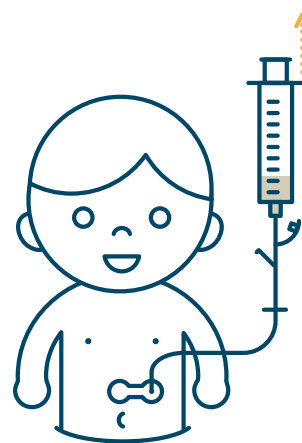


3. Attach a syringe to the end of the nasogastric tube and pull back gently on the plunger. If a small amount of pale gray or yellow stomach liquid is seen in the syringe, this is a sign that the tip of the feeding tube is in the stomach.
4. Follow your doctor's instructions for pushing the stomach liquid back into the stomach.
5. If you do not get any stomach fluid, turn your child onto the left side, and pull back again on the plunger. If you still do not get fluid back, remove the plunger and fill with 2-3 mL of air. Push the air into the tube. If your child chokes, coughs or has difficulty breathing, remove the feeding tube. This indicates that your child's feeding tube may be in the lung.
6. If your child does not have any breathing problems after flushing with air, wait for 15-20 minutes and then reattach the syringe and pull back on the plunger to obtain stomach contents.
7. Once you have 2-3 mL or more of fluid in the syringe, disconnect the syringe from the feeding tube.
8. Put a small amount of the stomach fluid on the pH paper and check the pH (acid in the stomach). If the fluid is acidic, (pH of 5.5 or less), the tube tip should be in the stomach.
Note: If your child is on antacids or other medications that can alter the pH of the stomach, check with your doctor for further instructions.
9. Remember to flush your child's feeding tube with water after obtaining stomach fluid. This will keep the tube from clogging.

CHECKING PLACEMENT OF YOUR CHILD'S GASTROSTOMY FEEDING TUBE

Here is how to do it:

1. Wash your hands with soap and warm water.
2. Check tube placement by attaching a syringe to the end of the feeding tube and pull back gently on the plunger. If a small amount of pale gray or yellow stomach liquid is seen in the syringe, this is a sign that the tip of the feeding tube is in the stomach.
3. Follow your doctor's instructions for pushing the stomach liquid back into the stomach.
4. Flush the tube with water to clear the tube and prevent clogging.
5. Remove the syringe from the feeding tube.



CHECKING GASTROSTOMY
TUBE PLACEMENT



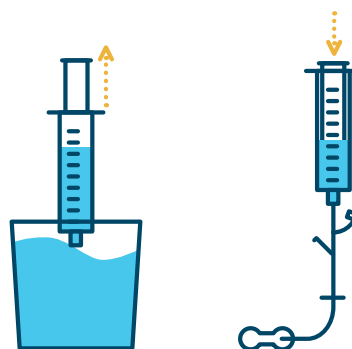
FLUSHING ALL TYPES OF FEEDING TUBES

Flushing the feeding tube routinely, or as directed, is important to keep the tube clean inside and to prevent clogging. A syringe filled with water is used to gently flush the feeding tube before and after each feeding. Flushing removes extra feeding from the tube and provides water for your child.

Here is how to do it:

1. Wash your hands with soap and warm water.
2. Place the tip of the syringe into the water and pull back on the plunger until there is 15 mL of water in the syringe (or the amount of water that your doctor has prescribed for flushing the tube). Attach the syringe to the feeding tube and slowly inject the water into the feeding tube.
3. Remove the syringe from the feeding tube after flushing.
4. Flush your child's feeding tube with water before and after each feeding.

Note: Extra water can be given through the feeding tube, as needed. If your child is on a fluid restricted diet, your doctor will provide recommendations for your child's daily fluid intake.



FLUSHING THE FEEDING TUBE
WITH WATER

ADMINISTERING THE FEEDING

Now that you have checked tube placement and flushed your child's feeding tube, it is time to begin the feeding. There are several methods that can be used. Your physician has prescribed the feeding method that is right for your child. Find your child's feeding method below and follow the instructions.

Note: Your child's doctor may provide additional guidance for feeding. This guidance may include specific amounts of fluid that should be used to flush the tube, and if your child requires additional water. Your child may be on a fluid restricted diet, and giving extra water through the feeding tube may not be advised by your doctor.

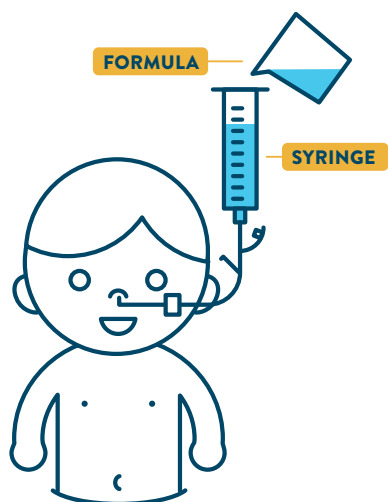
Bolus feeding instructions

Method #1 (gravity)

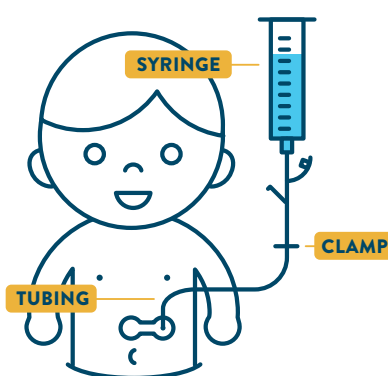
1. Wash your hands with soap and warm water.
2. Remove the plunger of the syringe and attach the syringe to the feeding tube.
3. Pour the formula into the syringe and allow the feeding to run into the stomach by gravity.



4. Repeat this process until all the prescribed feeding has been given.
5. Once the syringe is empty, add water to the empty syringe and allow it to flow in. This will clear the feeding from the feeding tube and provide extra water for your child.
6. Clean your child's feeding equipment as directed by your healthcare team.



Administer nasogastric feeding



Administer gastrostomy feeding

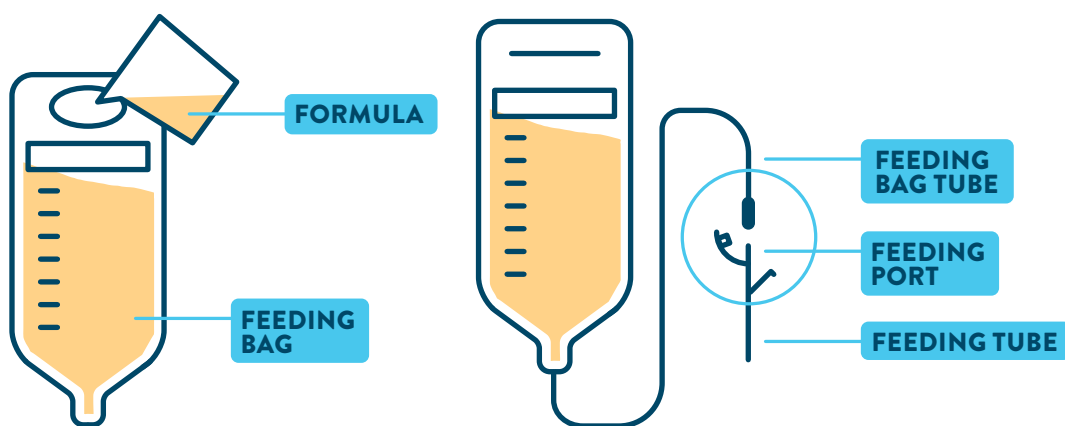
Method #2 (syringe)

1. Wash your hands with soap and warm water.
2. Place the tip of the syringe into the formula, then pull back on the plunger to fill the syringe.
3. Connect the syringe to the feeding tube.
4. Gently push the end of the syringe until all the formula has been given.
5. Disconnect the syringe from the feeding tube. Refill the syringe with feeding and repeat the process until all your child's feeding has been given.
6. Once the feeding is complete, place the tip of the syringe into the water. Pull the plunger back and fill the syringe with water.
7. Attach the syringe to the feeding tube and gently push the water into the feeding tube. This will clear any residual feeding from the feeding tube.
8. Clean your child's feeding equipment as directed by your doctor.



Intermittent feeding (gravity) instructions

1. Wash your hands with soap and warm water.
2. Pour the formula into the feeding bag and attach the bag in an elevated position on an intravenous pole (commonly called an IV pole).
3. Insert the tip of the feeding bag tubing into your child's feeding tube.
4. Open the clamp on the feeding bag and allow the formula to flow into the stomach.
5. When the feeding bag is empty of formula, add water to the feeding bag to rinse the bag and tubing. The water clears any left-over formula from the feeding tube, preventing clogs. The extra water is also important for your child's hydration.
6. Clean your child's feeding equipment as directed by your doctor.



POUR FORMULA INTO THE FEEDING BAG

Continuous (pump) feeding Instructions:

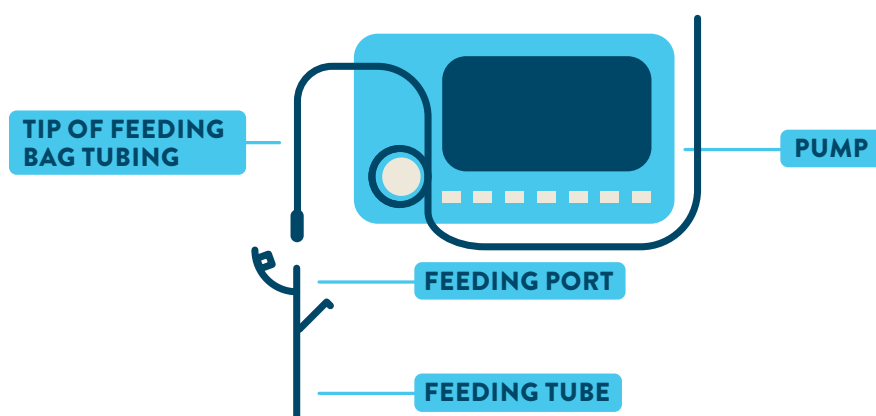
1. Wash your hands with soap and warm water.
2. A ready-to-use feeding bag or feeding container filled with formula is hung from an IV pole with a feeding pump attached. Your child may have the option or ability to use a backpack with their pump. Discuss this possibility with your healthcare provider.
3. Attach the feeding bag tubing to the pump.
4. Connect your child's feeding tube to the feeding bag tube.
5. Set the pump to the rate of feeding as prescribed by your child's physician.
6. Once turned on, the pump will automatically infuse your child's feeding. An alarm will sound when the feeding is complete.



7. Once the feeding is complete, water can be added to the feeding bag to clear the tubing of residual formula. The feeding bag is then disconnected from your child's feeding tube.
8. Clean your child's feeding equipment as directed by your doctor.

Note: Follow the instructions provided by your doctor for the infusion of your child's tube feedings and use of your child's specific feeding pump. Instructions for the routine maintenance of the feeding pump can be found in the Pump Operating Manual.

Note: Remember to write down the amount of each feeding and your child's response to the feeding on the *Tube Feeding Monitoring Checklist* (in the appendix of this booklet).



CONNECTING THE PUMP TO THE FEEDING TUBE



GIVING YOUR CHILD MEDICATION THROUGH A FEEDING TUBE

To make sure that your child's medications are effective, it is important to give the medications correctly as prescribed by your doctor. Use the *Medication Record* (in the appendix of this booklet) to keep a record of the medications you give your child.

HERE IS WHAT TO DO:

1. Stop the feeding before giving any medication. Your doctor will tell you how long the feeding should be held before you give the medication.
2. Wash your hands with soap and warm water.
3. Flush the feeding tube with water to remove any residual formula from the tube.
4. Use a syringe to give the medications.
5. Each medication should be given separately to avoid clogs.
6. Flush with water between each medication, and after all medications have been given.
7. Your doctor will tell you how soon your child's feeding can be restarted after the medications have been given.

Note: If you are unable to administer your child's medications as prescribed, contact the doctor for further instructions.

Note: When flushing your child's feeding tube, follow recommendations of your doctor, especially for infants and those on a fluid restriction.

Note: When giving both medications and a feeding, give the medications first.



MANAGING AND MAINTAINING YOUR CHILD'S FEEDING TUBE AND EQUIPMENT

In this section, we will cover the basics of how to manage and maintain the feeding tube and equipment. Proper maintenance keeps your child safe, and it keeps the equipment performing at its optimal level. Your doctor may give you specific instructions for managing your child's feeding tube.

Note: Remember to clean your child's feeding equipment after each use.

CLOGGED FEEDING TUBE

If you are unable to deliver the feeding, there may be a clog in the tubing. If your child uses a pump for feeding, the pump will alarm and stop the feeding infusion.

Here is what to do:

1. Wash your hands with soap and warm water.
2. Check to be sure there are no kinks in your child's feeding tube.
3. Fill a syringe with warm water, and attach the syringe to your child's feeding tube. Massage the feeding tube gently to loosen the clog and flush with water to clear the tube.
4. If the tube remains clogged, remove all fluid from the tube with a syringe. Next, inject warm water into the tube and clamp the tube for 20-60 minutes. The warm water will help break down the clog. Then, attach a syringe to the feeding tube and gently move the plunger in and out of the syringe several times to help dislodge the clog.
5. If the tube remains clogged, contact your doctor for further instructions.



Practical management tips to prevent issues:

1. Flush the feeding tube with water before and after each medication is given, and before and after each feeding. More information about flushing the feeding tube can be found on page 12 of this guide.
2. If your child is receiving continuous feedings, flush with water every 4-8 hours during the feedings. Your doctor will advise you on how much water to use.

NASOGASTRIC TUBE SITE COMPLICATIONS

Children with nasogastric tubes may experience irritation of the skin around or in their nose. This irritation may be caused by the movement of the tube, or by the adhesives that are used to secure the tube in place.

Here is what to do:

1. Clean the skin and nostrils with soap and water.
2. Reposition the tube and secure it with tape or a tube holder to prevent excessive movement of the tube.
3. If the nose or surrounding area is red, bleeding or is draining, contact your doctor for further instructions.

Practical management tips to prevent or minimize irritation:

1. Keep the area clean and dry. Consider using a topical ointment to lubricate the area.
2. Talk to your doctor about using a different type of tape or adhesive material.
3. If the nasogastric tube is reinserted at intervals, alternate between the use of the right and left nostril.
4. If bleeding or irritation continues, contact your doctor to discuss additional measures.

GASTROSTOMY AND JEJUNOSTOMY TUBE FEEDING COMPLICATIONS

The area around your child's gastrostomy or jejunostomy tube may become irritated. Irritation may be caused by movement of the gastrostomy tube, tube tract enlargement, or gastrostomy balloon deflation. Sometimes gastrostomy and jejunostomy tubes may have drainage around the insertion site. The drainage may be cloudy white, yellow, green, or red in color indicating irritation and possibly infection. You may also notice a bad odor, or that your child has a fever, both are possible signs of infection.



Your child's skin around the tube site may be reddened with:

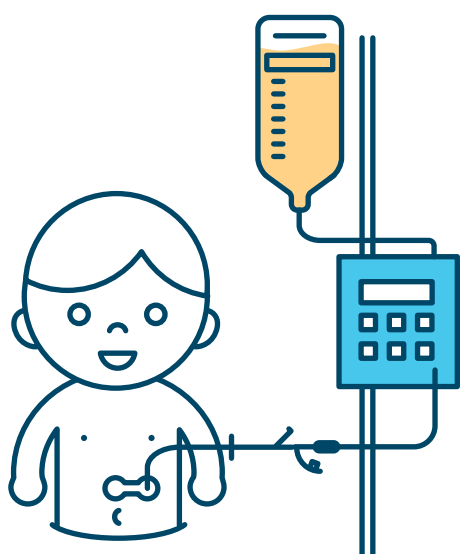
- Thick green or yellow drainage indicating an infection
- Raised papules (bumps) that may indicate a fungal infection
- Pus filled blisters or a burning sensation

Here is what to do:

1. Clean the skin around the tube daily with soap and water. Make sure that the area under the tube holder is also cleaned.
2. Evaluate the tube feeding site for redness and rashes. Check for leakage of fluids or formula around the site.
3. Contact your doctor when you notice signs of infection, which include redness around the site and a fever. Antibiotics or other medications may be needed to treat the infection.

Practical management tips to prevent issues:

1. Keep the skin around the tube clean and dry. Dressings are not recommended for daily use.
2. Do not use hydrogen peroxide or antibiotic ointments unless directed by your doctor. Hydrogen peroxide prevents healing and can cause skin irritation. Antibiotics may promote the growth of yeast if used for prolonged periods of time.
3. Secure the gastrostomy tube with a tube holder to prevent excessive movement of the tube. Excessive movement can cause irritation and lead to infection.
4. Check the condition of the skin around the gastrostomy tube prior to each feeding for redness or drainage. If your child has excessive drainage around the tube insertion site, your doctor may recommend the use of a dressing to absorb the fluid.



CHILD RECEIVING FEEDING
USING A FEEDING PUMP

FEEDING PUMP MAINTENANCE AND TROUBLESHOOTING

There are many types of feeding pumps. You will be instructed on how to operate and clean your child's specific pump, as the pump instructions are different for each manufacturer. Keep a copy of the pump's operating manual as a reference for periodic and routine maintenance. It is important to have your pump serviced according to the manufacturer's specifications. If you are experiencing any problems with your pump, contact the pump manufacturer or your home health agency.



RESOLVING ADVERSE PHYSICAL SYMPTOMS RELATED TO TUBE FEEDING

Your child may experience occasional gastrointestinal discomfort. Here we discuss some symptoms and how you can manage them at home.

ASPIRATION

Aspiration occurs when feeding enters the lungs, and it can be a serious complication of tube feeding. Aspiration can cause coughing or choking and may lead to difficulty breathing.

Here is what to do:

1. If you suspect that your child has aspirated, stop the feeding.
2. Remove the nasogastric tube (if in place), and call 911 if your child is having difficulty breathing.

Practical management tips to prevent aspiration:

1. Check placement of the feeding tube tip prior to each feeding.
2. Keep your child elevated at a 30-45° angle during feeding and for one hour after the feeding. This allows the feeding to drain naturally from the stomach into the small intestine.
3. Use extra caution when your child has an acute upper respiratory infection or viral illness.
4. If your child is experiencing bloating or vomiting, do not start the feeding. Contact your doctor for further instructions.

CONSTIPATION

Constipation occurs when your child's stool is hard and difficult to pass. Constipation can be caused by the lack of water or fiber in the diet. Some medications can also cause constipation.

Here is what to do:

1. Give your child extra water to help soften the stool.
2. Contact your doctor if your child's constipation continues.



Practical management tips to prevent constipation:

1. Provide your child with enough water each day to prevent hard stools.
2. If appropriate, allow your child to play and exercise as much as possible. Exercise is important in maintaining normal bowel function.
3. Review the medications that your child is taking with your pharmacist or doctor to determine if there are other options.
4. Check with your doctor about changing your child's formula. Formulas with additional fiber may be needed to keep your child's bowel habits regular.

DEHYDRATION

Dehydration occurs when your child does not get enough water or is experiencing fluid loss from conditions such as diarrhea or fever. Some signs that your child may be dehydrated include excessive thirst, dry mouth, and small amounts of urine. The urine may be dark yellow in color, with darker colors indicating more severe levels of dehydration.

Here is what to do:

1. Give your child small amounts of water frequently until the symptoms resolve.
2. If your child has a temperature, profuse sweating, diarrhea, or an increase in wound drainage, contact your doctor.

Practical management tips to prevent dehydration:

1. Be sure to give your child the prescribed amount of water each day as recommended by your child's doctor.
2. Use water before and after each feeding to clear the tube and to prevent dehydration.
3. Additional water may be given between feedings and may be needed during periods of activity.

FEEDING INTOLERANCE AND DIARRHEA

Your child may experience feeding intolerance during tube feeding. Feeding intolerance may be caused by feeding too fast, using formula that is too cold, or by your child lying flat during feeding.

Symptoms of feeding intolerance include:

- Irritability
- Nausea, vomiting, or stomach pain
- Heartburn and reflux
- Gas, bloating, cramping and diarrhea



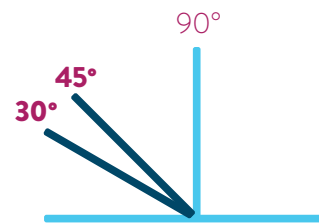
Diarrhea can be a different symptom of feeding intolerance. Four or more watery bowel movements per day, or an increase in stool volume above your child's normal volume, is considered diarrhea. Diarrhea may result from feeding your child too fast, side effects of medications, lack of fiber in the formula, or bacterial contamination in the formula which can occur during preparation. Always remember to wash your hands before you handle your child's feeding tube or prepare feedings. Another point to consider is that your child may be having difficulty tolerating the formula that they are being given.

Here is what to do:

1. Consider slowing down the rate of feeding. Sometimes slowing the feeding improves the child's tolerance.
2. Review the medications that your child is taking with your pharmacist or doctor to determine if there are other options.
3. Talk to your doctor about changing the type of formula that you are giving your child. However, your doctor may be cautious about frequently changing formulas.
4. If the symptoms have not resolved within 8-12 hours, contact your doctor for further instructions.

Practical management tips to prevent feeding intolerance and diarrhea:

1. If the formula is in the refrigerator, remember to take it out and let it warm to room temperature for 30 minutes before feeding.
2. Wash your hands with soap and warm water.
3. Wipe the top of the container with an alcohol wipe before pouring the formula into the feeding container or syringe.
4. Formula containers should be stored in the refrigerator after opening, and all formula should be used within 24 to 48 hours after opening.
5. Keep your child elevated at a 30-45° angle during feeding and for one hour after feeding. This allows the feeding to drain naturally from the stomach into the small intestine.
6. Maintain consistency with your child's rate of feeding. Do not try to "speed up" the feeding.
7. If feeding intolerance continues to be a problem for your child, contact your doctor about adjusting the rate of feeding, or switching to a different formula that may be better tolerated.





GASTROESOPHAGEAL REFLUX

Gastroesophageal reflux (GER) occurs when the feeding, stomach acid, and bile back up into the esophagus and cause pain and irritation. Symptoms of GER generally occur after feeding and include irritability, stomach pain, and occasionally trouble breathing after feeding.

Here is what to do:

1. Consider slowing down the rate of feeding. Sometimes slowing the feeding improves the child's tolerance.
2. If the symptoms have not resolved within 8-12 hours, contact your doctor for further instructions.

Practical management tips to prevent gastroesophageal reflux:

1. Check the placement of your child's feeding tube tip prior to each feeding.
2. If the formula is in the refrigerator, remember to take it out and let it warm to room temperature for 30 minutes before feeding.
3. Keep your child elevated at a 30-45° angle during feeding and for one hour after feeding. This allows the feeding to drain naturally from the stomach into the small intestine.
4. If your child is experiencing bloating or vomiting, do not start or continue the feeding. Contact your doctor for further instructions.



NAVIGATING YOUR DOCTOR VISITS



Preparing for doctor's visits is an important step to ensuring that your child's care is optimized. One way to simplify things is to think of your appointment in 3 parts:

BEFORE THE VISIT:

- All the forms mentioned below are located in the appendix at the end of this booklet.
- Review your child's Tube Feeding Nutrition Plan.
- Review your child's Tube Feeding Monitoring Checklist.
- Review your child's Medication Record.
- If there is a specific problem, identify the signs and symptoms, when it started, how you have managed it and what was the result.

DURING THE VISIT:

- You can use the Tube Feeding Nutrition Plan, Tube Feeding Monitoring Checklist and Medication Record to share information during your doctor's visit.
- Revise your child's Tube Feeding Nutrition Plan if changes are made during the visit.
- Confirm next steps and follow-up.

AFTER THE VISIT:

- If your child's problem or issue has not resolved within the agreed upon timeline, contact your physician to discuss other treatment options.
- Continue using the forms to track your child's progress and to communicate with your doctor.



COMMUNITY SUPPORT

There may be times when you need additional support while caring for your child, here are three organizations that can help.

ASPEN

The American Society for Parenteral and Enteral Nutrition is a nonprofit professional organization whose mission is to improve patient care by advancing the science and practice of clinical nutrition and metabolism.

ASPEN's resources include:

- Ask About Your Child's Nutrition Poster (English and Spanish)
- Pediatric Nasogastric Tube Placement and Verification: An Instructional Video for Caregivers (English and Spanish)
- What is Enteral Nutrition? (English and Spanish)



Visit nutritioncare.org

THE FEEDING TUBE AWARENESS FOUNDATION

This nonprofit organization was founded by parents with the mission to help other parents by sharing practical experience for tube-feeding infants and children, and to raise positive awareness of tube feeding so that families have the support they need.

The Feeding Tube Awareness Foundation's resources include:

- A network of parents of tube fed children
- Resources on tube feeding basics and troubleshooting (see Appendix for list of available resources)
- Emotional and "Navigating Life" support
- Product and supply resources



Visit feedingtubeawareness.org



OLEY FOUNDATION

The Oley Foundation is a nonprofit organization whose mission is to enrich the lives of those living with home intravenous nutrition (parenteral) and tube feeding (enteral) through education, advocacy, and networking.

Oley's Resources include:

- Access to a network of clinical experts and caregivers involved with home tube feedings
- Education and troubleshooting materials (see Appendix for list of available resources)
- Equipment and supplement exchange
- Support groups
- Bi-monthly newsletter and annual conference for patients, family members and caregivers



Visit [oley.org](https://www.oley.org)



SPECIAL CONSIDERATIONS

Giving your child a bath and allowing them to swim

You should sponge bathe your child for the first two weeks after the tube is placed. After the tube feeding site heals (usually about 2 weeks) it may be safe to give your child a bath. Discuss with your healthcare team the recommended timeline for giving your child a bath and allowing them to swim.

Transitioning from parenteral nutrition (intravenous) to tube feeding

Transitioning from parenteral nutrition to tube feeding is an exciting time, but this time is also filled with questions on how to ensure that your child gets optimal nutrition. Tube feeding will be started while your child is still receiving parenteral nutrition. This approach ensures that all the nutritional needs of your child are being met during the transition process.

Your doctor will advise you on the transition schedule for your child, here are some guidelines to follow:

- Transitioning from parenteral nutrition to tube feeding will be initiated when your child's tube feeding is providing about 33%-50% of their daily nutrition needs.
- Once the tube feeding is providing 60-75% of your child's nutrition requirements, the parenteral nutrition may be discontinued.
- In some cases, it may be necessary to continue parenteral nutrition until 75% or more of your child's nutrition needs are met by tube feeding. This approach will support optimal growth and development. Your doctor will inform you if this is necessary.

Transitioning from tube feeding to oral feeding

Transitioning from tube feeding to oral feeding requires close monitoring to make sure your child does not lose weight during the process. Your doctor will let you know when he or she thinks your child is ready to begin the transition.

Sometimes a speech evaluation will be done to ensure your child can chew and swallow effectively. Once your child has been evaluated and normal swallowing is verified, oral foods can be introduced.

Until your child meets all nutrition requirements from oral intake, it is advised to keep the feeding tube in place.



Follow these guidelines to help your child transition to oral feeding:

- Allow your child to help choose what foods to eat at mealtime and for snacks.
- Tube feeding should be stopped for at least 1 hour prior to mealtime to stimulate your child's appetite.
- Tube feeding can be given after meals to supplement your child's intake.
- Once your child meets 50% of nutritional needs from food for 2-3 consecutive days, the amount of tube feeding can be decreased. Your doctor will provide guidance on this transition, and when it is appropriate for your child.

Care providers outside of the home

- Have a discussion with your child's school and day care center providers to determine a plan of action if your child's tube is accidentally removed. It may be advised to have an emergency kit available.

PREPARING FOR DISASTERS

Being prepared for unexpected situations can often mean the difference between inconvenience and crisis.

- Storms can disrupt electrical power for minutes or hours, or if severe enough, for days and even weeks. Electricity is needed to run your refrigerator and for operating your child's enteral feeding pump.
- Tube feeding supply deliveries can be disrupted due to high winds, blocked roads, flooding, and gas shortages.

A good rule to follow to avoid disruption in your child's feeding schedule is to have a disaster plan. This plan should include having several days' worth of supplies in your home.

These supplies should include:

- Your child's formulas and medications
- Enteral feeding supplies and pump batteries
- Disinfectants for hand washing, cleaning equipment and work surfaces
- Bottled water for tube flushing and hydration

You can find more information on disaster preparedness in the appendix of this booklet. Take a few minutes to review these recommendations, and make a disaster plan that is right for your child.

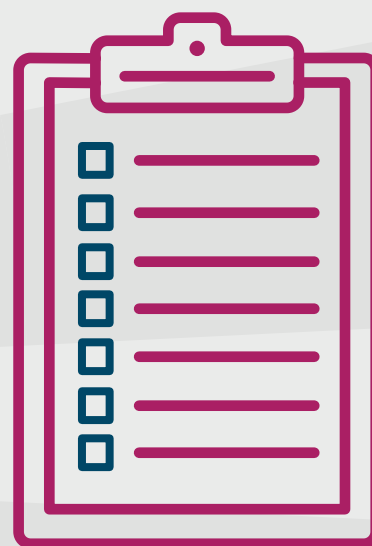


SUMMARY

Now that you've learned the basics of tube feeding, you can be confident about managing your child's tube feeding. Your child will get the right nutrition to grow and thrive.

YOU'VE MASTERED:

- ☒ TUBE FEEDING BASICS
- ☒ MANAGING AND MAINTAINING YOUR CHILD'S FEEDING TUBE
- ☒ MANAGING PHYSICAL SYMPTOMS
- ☒ ADMINISTERING MEDICATIONS
- ☒ NAVIGATING YOUR CHILD'S DOCTOR VISITS
- ☒ IDENTIFYING COMMUNITY RESOURCES
- ☒ ADDRESSING SPECIAL FEEDING ISSUES



Remember:

You're not alone. Your healthcare team is here to answer immediate questions, and other parents just like you are available for support. They're here to help you and your child succeed!

Every important journey begins with a single step. **You're on your way.**

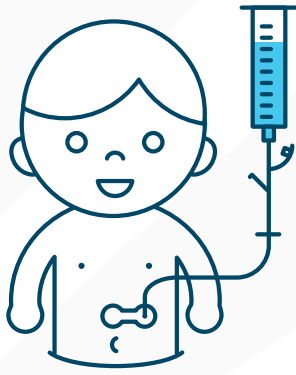


APPENDIX

Tube feeding management forms

Your child's tube feeding may seem complicated but by keeping daily records you will find that the process is simplified and that you are able to discuss your child's care easily with your doctor or other healthcare providers.

The Tube Feeding Management forms help you manage your child's care and provides your doctor and other healthcare providers with a comprehensive summary of your child's progress while on tube feeding. The Tube Feeding Management forms should be taken to each doctor's visit.



TUBE FEEDING NUTRITION PLAN

The Tube Feeding Nutrition Plan provides an overall summary of your child's tube feeding care plan. Keeping this form updated provides an accurate record of your child's feeding plan that can be referred to by other caregivers and healthcare providers unfamiliar with your child's care.

Child's Name _____ Age _____

Address _____ Condition _____

Contact information _____

Prescribing Physician name/number _____

Home Health Agency name/number _____

Hospital name/phone number _____

Feeding Tube

Type/manufacturer of feeding tube/
french size _____
Date of feeding tube placement _____
Site care _____
Tube holder type _____

Formula

Type/manufacturer _____
Inspection, storage, preparation for
feeding _____
Administration and hangtime _____

Feeding Pump

Manufacturer _____
Instructions for use _____

Feeding Plan

Feeding Schedule _____
Water flushes _____
Medications administration via tube _____
Oral intake _____
When to call the doctor _____

Ordering supplies

Manufacturer name/contact information _____
Supplies _____

Community Resources

American Society for Parenteral
and Enteral Nutrition (https://www.nutritioncare.org/About_Clinical_Nutrition/Patients_Caregivers/)
Oley Foundation (www.oley.org)
Tube Feeding Awareness Foundation
(www.feedingtubeawareness.org)
Other _____

Emergency numbers

Electric Company _____
Other _____

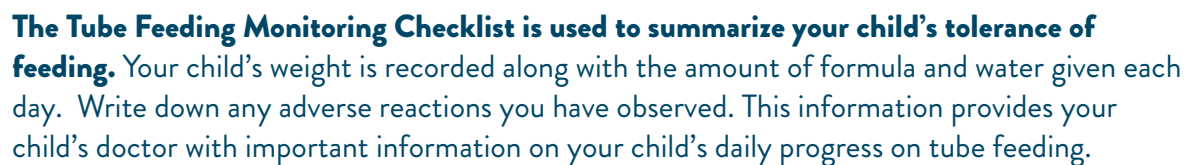
Additional information:



TUBE FEEDING MONITORING CHECKLIST

DATE:	MON.	TUES.	WED.
WEIGHT			
AMOUNT OF FORMULA GIVEN: VOLUME CALORIES RATE			
ORAL FEEDS			
AMOUNT OF WATER GIVEN			
URINE: COLOR/ODOR # OF DIAPER CHANGES			
STOOL CONSISTENCY: LIQUID (#/DAY) SOFT (#/DAY) HARD (#/DAY)			
CONSTIPATED			
NAUSEA			
VOMITING # OF EPISODES			

DATE:	MON.	TUES.	WED.
SKIN: REDNESS DRAINAGE GRANULATION TISSUE SKIN BREAKDOWN			

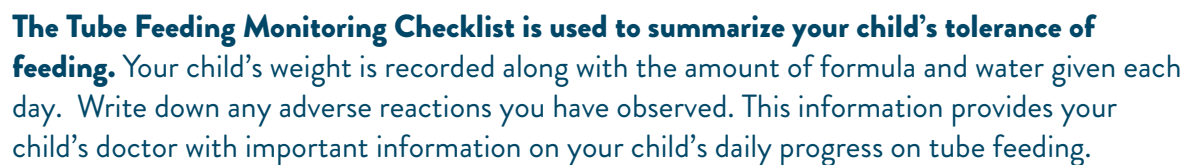




TUBE FEEDING MONITORING CHECKLIST

DATE:	MON.	TUES.	WED.
WEIGHT			
AMOUNT OF FORMULA GIVEN: VOLUME CALORIES RATE			
ORAL FEEDS			
AMOUNT OF WATER GIVEN			
URINE: COLOR/ODOR # OF DIAPER CHANGES			
STOOL CONSISTENCY: LIQUID (#/DAY) SOFT (#/DAY) HARD (#/DAY)			
CONSTIPATED			
NAUSEA			
VOMITING # OF EPISODES			

DATE:	MON.	TUES.	WED.
SKIN: REDNESS DRAINAGE GRANULATION TISSUE SKIN BREAKDOWN			





MEDICATION RECORD

The Medication Record is used to record all the medications that are given to your child each day.

DATE	TIME	MEDICATION	DOSE





NOTES

Remember to write down your observations or questions you may have about your child's tube feeding. Take these notes to your child's doctor appointments.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



GLOSSARY

The Glossary of Terms provides a definition of many medical terms that you need to learn as you manage your child's tube feeding.

ABDOMEN: The body space between the chest and the pelvis. This space houses the stomach, liver, gallbladder, spleen, pancreas, small bowel (intestine), large intestine and adrenal glands.

ABDOMINAL WALL: The abdominal wall represents the boundaries of the abdominal cavity.

ABSORPTION: Absorption of nutrients by the digestive system.

BALLOON PORT: A port on the proximal end (end furthest away from the abdomen) of a gastrostomy tube where water is inserted to inflate the balloon. There is a plastic sleeve around the port that tells how much water is needed to inflate the balloon.

BLOATING: Swelling and tightness of the abdomen, typically caused by fluid, gas or air.

BOLUS FEEDING: Formula is placed in a syringe or feeding bag and flows slowly into the feeding tube; the height of the syringe controls the feeding rate.

BUMPER: Found on the distal end of the feeding tube, (the end that is inside the stomach) it helps hold the tube in place. Some gastrostomy tubes are held in place in the stomach by a solid silicone bumper, while others are held in place with a water-filled balloon.

CANDIDIASIS: An infection caused by yeast. It can develop on the skin around the feeding tube.

CONTINUOUS FEEDING: Tube feeding where the formula drips slowly all day.

DEHYDRATION: A condition in which the body does not have enough water.

DELAYED GASTRIC EMPTYING: A condition that slows or stops the movement of food from the stomach to the small (bowel) intestine.

ESOPHAGUS: The muscular tube leading from the mouth to the stomach.

EXTERNAL SKIN DISK: Disk that holds the tube in place as it exits the body. Its purpose is to prevent lateral tube movement which could contribute to leakage of gastric contents onto the skin.

FEEDING PORT: The main port of the feeding tube. Formula is delivered to the patient by connecting a feeding set or syringe to this port.

FEEDING SET: Tubing that is connected to a feeding container and delivers formula into the stomach or small bowel (intestine).

FEEDING TUBE: A tube into the stomach or small bowel (intestine) through which formula flows.

FLUSHING: The process of pushing water through the tube to prevent tube clogging.

FRENCH SIZE: A measuring system used to define the diameter of a feeding tube. The larger the number, the bigger the diameter.

GASTROSTOMY TUBE (G-TUBE): A feeding tube that goes into the stomach through a stoma.

HYPERGRANULATION TISSUE: Thick, red, raised tissue that can form around the feeding tube where it enters the abdominal wall.

GRAVITY FEEDING: Feeding method where formula flows from a container, through a feeding set and into the patient.

INTERMITTENT FEEDING: Feeding method in which formula is given 3 to 8 times a day.

JEJUNOSTOMY TUBE (J-TUBE): A feeding tube that goes into the small intestine.



JEJUNUM: The second part of the small bowel (intestine).

LOW-PROFILE GASTROSTOMY TUBE (BUTTON):

A gastrostomy tube that lies flat against the abdomen.

MALABSORPTION: Failure to absorb certain nutrients, vitamins and minerals from the intestinal tract into the bloodstream.

MALDIGESTION: Inability to digest food in the intestine.

NASOGASTRIC (NG) TUBE: A feeding tube that goes from the nose to the stomach.

NASOJEJUNAL (NJ) TUBE: A feeding tube that goes from the nose to the jejunum.

NAUSEA: Having stomach upset with the urge to vomit.

PERISTOMAL INFECTION: Infection of the tissue around the feeding tube.

PEG (PERCUTANEOUS ENDOSCOPIC GASTROSTOMY): A non-surgical way to place a feeding tube into the stomach through the abdominal wall.

PEJ (PERCUTANEOUS ENDOSCOPIC JEJUNOSTOMY): A non-surgical way to place a feeding tube into the jejunum through a gastrostomy tube.

PRIME THE FEEDING SET: To pour the formula into the feeding container and let it flow to the end of the feeding set to remove the air in the set prior to connecting it to the feeding tube.

PUMP FEEDING: Feeding method in which a mechanical pump moves formula through the feeding tube.

RECONSTITUTE: To restore to a former condition by adding water.

RESIDUAL: The formula that remains in the stomach from the last feeding.

SMALL BOWEL (INTESTINE): The part of the digestive tract between the stomach and large intestine that digests and absorbs nutrients.

SORBITAL: A sugar alcohol used in liquid medications that can cause diarrhea in some patients.

STOMA: Opening in the abdominal wall through which a gastrostomy tube or jejunal tube enters the body.

SYRINGE: A hollow, plastic tube with a plunger used to draw fluid out of or inject fluid into a feeding tube.

SYRINGE FEEDING: Feeding method in which formula flows from a syringe into a feeding tube or is injected into the feeding tube using the plunger on the syringe.



ADDITIONAL PARENT AND CAREGIVER SUPPORT MATERIALS

Check out the valuable resources below to help you manage your child's care.

NUTRITION SUPPORT ORGANIZATIONS AND FOUNDATIONS		
ORGANIZATION	LINK	RESOURCES
American Society for Parenteral and Enteral Nutrition: The NOVEL Project	https://www.nutritioncare.org/NOVEL/	Caregivers' instructional videos on nasogastric tube placement and verification (English/Spanish) Caregivers' Instructional booklet- "A Guide for Home Nasogastric Tube Feeding Management in Children"
Feeding Tube Awareness Foundation	https://www.feedingtubeawareness.org/	Foundation focused on providing Information on tube feeding to parents and caregivers
	https://www.feedingtubeawareness.org/feed-ing-pump/	Information on feeding Pumps & Sets
	https://www.feedingtubeawareness.org/tube-feed-ing-basics/tubetypes/	Information on types of feeding tubes
	https://www.feedingtubeawareness.org/tube-feed-ing-basics/introductions/education-materials/	Training presentation on tube feeding for teachers, aides, and school nurses
	https://www.feedingtubeawareness.org/wp-content/uploads/2015/06/Emergency_Kit_Guide.pdf	Emergency kit guide
The Oley Foundation	https://oley.org/	Foundation dedicated to patient and caregiver support
	https://oley.org/page/emergencyprepared	"Home Parenteral and Enteral Nutrition During Natural Disasters: A Guide for Clinicians and Consumers"



DISEASE SPECIFIC FOUNDATIONS		
ORGANIZATION	LINK	RESOURCES
Association of GI Motility Disorders, Inc.	https://www.agmdhope.org/	Gastrointestinal motility disorders information
Crohn's and Colitis Foundation	https://www.crohnscolitisfoundation.org/	Crohn's and Colitis information
Gastroparesis Patient Association for Cure and Treatment, Inc.	https://www.g-pact.org/	Gastroparesis information
Mito Action (Mitochondrial disease information)	https://www.mitoaction.org/	Mitochondrial disease information
Short Bowel Syndrome Foundation	http://shortbowelfoundation.org/	Short bowel syndrome information

Visit Abbott Nutrition Health Institute at anhi.org for more great resources.



**OUR NUTRITION
SCIENCE RESOURCES
MAKE IT EASIER FOR
YOU TO HELP YOUR
CHILD THRIVE.**

VISIT anhi.org TODAY

MISSION

Connect and empower people through science-based nutrition resources to optimize health worldwide.

VISION

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EDUCATION • RESOURCES

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