

Parents' Guide to Pediatric Tube Feeding





Contents

	Introduction.....	3
	Finding Community Support.....	4
	Understanding the Tube Feeding System	6
	Monitoring Your Child's Response to Tube Feeding.....	8
	Navigating Your Doctor Visits.....	18
	Tube Feeding Monitoring Checklist.....	20
	Medication Record.....	28
	Notes.....	30
	Glossary.....	32



Introduction

We know that tube feeding brings major life changes to your entire family. But you're not alone. We hope you find this guide a useful, practical resource that can help your child tube feed successfully at home.

You'll find step-by-step instructions on handling issues you face every day, from monitoring your child for infections to preparing for a doctor's appointment. The guide includes worksheets (P. 20-31) that make it simple to record important information about your child's progress. We've also added a helpful glossary (P. 32-34) that you can refer to if you come across any unfamiliar terms.

While technical and medical support form the foundation of tube feeding success, we believe that emotional support is just as important. Hopefully, you'll find resources in this guide that make your family's journey easier.



Finding Community Support

The community organizations listed here offer support and guidance to help you and your child adjust successfully to life with tube feeding. Visit the links below to find educational resources, support groups and the opportunity to connect with other families in your situation.

The Oley Foundation

The Oley Foundation is a nonprofit organization for people who depend on home enteral (tube) feeding or parenteral (intravenous) feeding.

Resources include:

- Access to a network of individuals and caregivers who are involved in tube feeding at home
- Education and troubleshooting materials
- Support groups
- Bi-monthly newsletter
- Equipment and supply exchange
- Annual conference for patients, family members and caregivers



www.Oley.org

The Feeding Tube Awareness Foundation

This nonprofit, volunteer-run organization was founded by parents of tube-fed children. Its mission is to provide a forum for parents to share their practical experience with tube feeding and to raise awareness of tube feeding in the community. You'll enjoy access to:

- A network of parents of children who tube feed
- The world's largest support group for tube feeding families (Facebook.com/FeedingTubeAwareness)
- Resources to help you care for your tube-fed child
- Education and troubleshooting materials



www.feedingtubeawareness.org



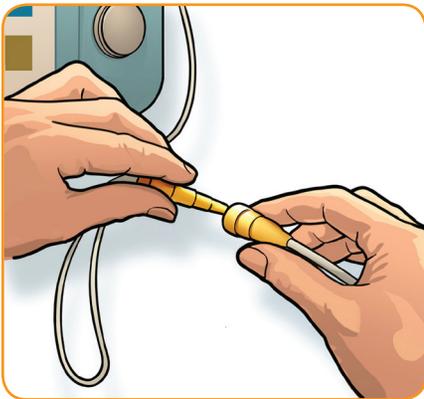


Understanding the Tube Feeding System

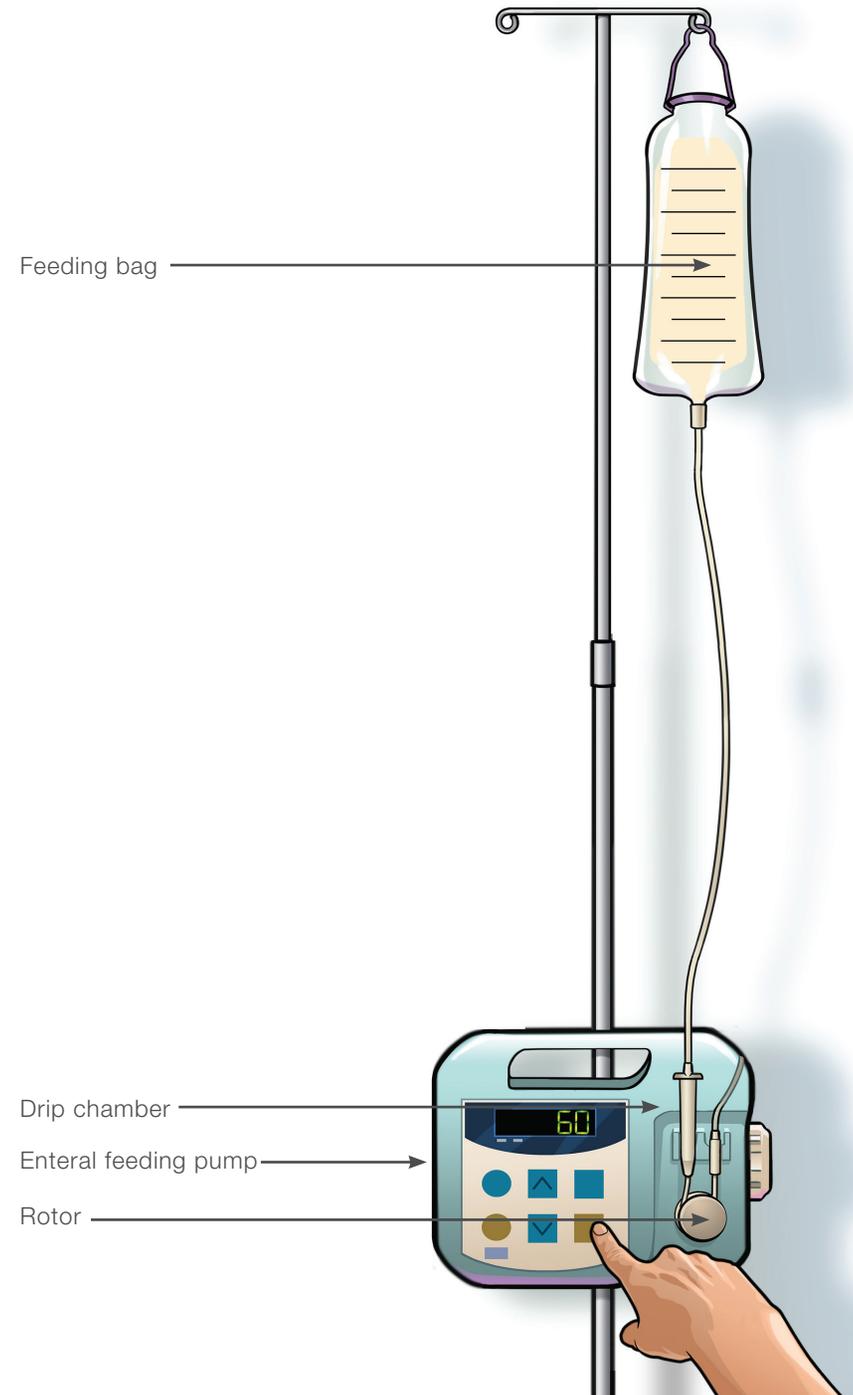
A tube feeding system has a lot of parts and pieces. This diagram can help you see how they all work together.



Pouring formula into feeding bag



Connecting feeding bag tubing to feeding port





Monitoring Your Child's Response to Tube Feeding

By keeping close track of your child's reactions to tube feeding, you provide accurate information for your doctor – and save yourself time. When you write things down right away, you don't have to spend time later trying to recall important details when they're no longer fresh in your mind.

The Tube Feeding Monitoring Checklist (P. 20-27) is an easy way to track signs and symptoms that can provide information important to your child's health. **The Medication Record (P. 28-29)** allows you to monitor your child's medication schedule. Sharing these records with your physician can help him or her identify and address any issues that may arise.



Medication Record



Tube Feeding Monitoring Checklist

Feeding Intolerance

It is important to monitor and document the presence (or absence) of symptoms associated with intolerance, as it can lead to complications such as dehydration.

Typically, patients experiencing intolerance to tube feeding will have more than one of these symptoms.

When patients show signs associated with intolerance, it is important to determine whether the intolerance is related to the formula or something else. Please inform your doctor if you suspect your child is experiencing any symptoms of intolerance.

Look for:

- Nausea
- Vomiting
- Diarrhea
- Bloating
- Constipation
- Abdominal discomfort



Causes of Intolerance Symptoms

- **The stomach, esophagus or intestine may not be working properly due to one of these issues:**
 - Infection
 - Delayed gastric emptying
 - Malabsorption
 - Maldigestion
- **Type of formula doesn't meet the patient's needs.**
- **Formula is spoiled from contamination during preparation, storage or administration.**
- **Formula is going in too fast.**
 - When your child is new to tube feeding, feedings should be started and advanced at a slow rate. This allows your child's GI tract to adjust to the formula and method of delivery.
 - Bolus feeding should be reserved for those tube feeders that have demonstrated tolerance to a continuous method of feeding.
- Small bowel (jejunal feeding or J-Tube feeding) should be given with a feeding pump at a controlled rate.
- **Formula is the wrong temperature.** Taking formula out of the refrigerator and administering it before it has had time to rise to room temperature can lead to abdominal cramping and other intolerance-related symptoms.
- **Medication side effects.** Many medications in liquid form contain sorbitol, a sugar alcohol that can cause diarrhea in some patients. In addition, medications can also interact with each other, leading to GI symptoms.
- **Patient is lying flat while receiving tube feeding.**
- **Volume of formula is too large.**



A tube-fed patient's head should be raised 30 degrees or more.

Nausea, Vomiting and Abdominal Discomfort

Possible Causes	Prevention and Treatment
Not tolerating the formula	<ul style="list-style-type: none"> • Work with your health care provider to determine cause and talk to your doctor about switching to a tolerance formula.
Formula going in too fast	<ul style="list-style-type: none"> • Begin at a slow rate. • Increase the rate and amount gradually over 24-48 hours.
Formula spoiled or contaminated during preparation	<ul style="list-style-type: none"> • Wash and dry hands prior to preparing a feeding or touching the feeding tube. • Avoid touching any part of the feeding tube system that will come in contact with the formula. • Record date and time on can after it is opened and store covered in the refrigerator. • Discard unused formula after 48 hours or as recommended by formula manufacturer.
Incorrect patient position during and after feeding	<ul style="list-style-type: none"> • Confirm tube placement prior to feeding if recommended by your health care provider. • Elevate patient's head 30 degrees or more by propping up in bed or on a couch . • Keep your child in a raised position for at least one hour after feeding.
Stomach, esophagus or intestine not working properly	<ul style="list-style-type: none"> • The doctor may need to do an examination or other tests.

Diarrhea

Possible Causes	Prevention and Treatment
Medication side effects	<ul style="list-style-type: none"> • Ask the doctor about substitute medications. • Diarrhea can be worsened by antibiotics or by medications containing sorbitol, magnesium or phosphorus.
Not tolerating the formula	<ul style="list-style-type: none"> • It is possible for a patient to be intolerant of a formula. • For these patients, it may be necessary to switch to a different formula. • Switching a child with diarrhea to a fiber-containing formula can sometimes help alleviate the diarrhea.
Malabsorption, maldigestion or impaired GI function	Your child may benefit from a formula that contains specialized ingredients to support absorption and tolerance.

Bloating and Constipation

Possible Causes	Prevention and Treatment
Not taking enough liquids or fiber	<ul style="list-style-type: none"> • Ask the doctor how much extra water you should be giving your child each day. • If the current formula does not contain fiber, discuss changing to a fiber-containing formula with the doctor.
Medication side effects	<ul style="list-style-type: none"> • Ask the doctor if any of your child's medications could be causing constipation. • Pain meds, iron and anti-diarrheals are common medications that can contribute to the development of constipation. • Ask if there is an alternative medication that may have fewer side effects.

Tube Site Complications

Prevention and early intervention are key to decreasing the risk of complications associated with the feeding tube site. (For comparison, here is a healthy stoma located right.) Tube site complications can include:



A healthy stoma site

■ Hypergranulation Tissue

Thick, red, raised tissue that can form around the feeding tube where it enters the body. The tube site will be red and may bleed easily. In some cases, a clear or cloudy discharge may be present. This discharge can lead to breakdown of the skin at the tube site.

■ Wound Infections

These infections can occur with all types of abdominal feeding tubes. Infection usually is limited to the skin and subcutaneous tissue, although more severe infections can occur. The two primary types of wound infections are Candidiasis and Peristomal infections.

- **Candidiasis** is an infection of the skin surface caused by yeast. It can be identified by redness; skin breakdown; small, inflamed, pus-filled, blister-type lesions and a burning sensation at the entrance site.
- **Peristomal infections** invade the tissue surrounding the tube. Identifying features of this type of infection include redness, tenderness, swelling and firmness at the site, pus-filled drainage from the site and possible fever.

Look for:

- Stoma at skin level
- Not red or pink in color at the site
- Not moist or wet in appearance
- No rash, ulcers or swelling in the surrounding skin
- No gap between base of stoma and skin (no inflammation or excess skin at site)

■ Leakage Around G-Tube

Drainage of any type of liquid around the exit site of the tube places the patient at risk for skin breakdown and infection. Leakage is considered a symptom of an underlying problem such as:

- Inward or outward movement of the tube
- Tube tract enlargement
- Bolus feeding or overfeeding
- Balloon deflation

Types of discharge from around the tube site can include: gastric content; semi-thick, red drainage; tube feeding formula; medications or air.

Hypergranulation Tissue

Causes	Prevention and Treatment
Trapped moisture	<ul style="list-style-type: none"> • Keep skin around the tube dry. Clean site with soap and water or non-toxic skin cleanser. • No dressing is necessary unless your child is likely to pull at tube. • Protect skin with a waterproof ointment when drainage is present. • Ask the doctor if he or she feels that the granulation tissue needs to be reduced.
Foreign body reaction, resulting in rapid development of thick, red tissue (seen more often in children)	
Excessive tube manipulation	

Look for:

- Thick, red, raised tissue around the stoma site
- Bleeding at the tube site
- Clear or cloudy discharge



A stoma site with hypergranulation tissue

Leakage Around the G-Tube

Causes	Prevention and Treatment
Inward and outward movement of the tube	<ul style="list-style-type: none"> • Verify tube placement using method recommended by your physician. • Stabilize the feeding tube externally by adjusting the external skin disk, allowing for slight movement of the tube. • Infuse medications and formula slowly. • Monitor fluid volume of the balloon to ensure proper inflation.
Tube tract enlargement caused by excessive back-and-forth motion	
Rapidly infusing formula via bolus	
Balloon bumper that is defective or needs more water	

Tube Site Infections

Causes	Prevention and Treatment
Compromised immune system	<ul style="list-style-type: none"> • Prevent the tube from accidental removal by making sure that the external skin disk is placed properly – close to the skin.
Displacement of the tube	
	<ul style="list-style-type: none"> • Verify tube placement using method recommended by your physician. If tube is out of place, notify physician to receive additional instructions. • Do not feed the patient through a feeding tube if a peristomal wound infection is suspected. This could spread or worsen infection. Contact your physician to determine if systemic antibiotics should be given.



An infected stoma site

Look for:

- Redness
- Tenderness
- Swelling and firmness at the site
- Pus-filled drainage
- Possible fever
- Foul odor

Candidiasis (Yeast Infection)

Causes	Prevention and Treatment
Infrequent dressing changes	<ul style="list-style-type: none"> Remove the cause. Preventing moisture buildup is the most important intervention. Keep area dry and open to air – a fan or hair dryer on a cool setting may be used to dry the area. Ask your doctor if an antifungal powder or cream would be helpful.
Prolonged skin contact with moisture (wet dressings)	
Susceptibility to yeast (immune-compromised, diabetic)	
Patients on antibiotic therapy	



A stoma site with yeast infection

Look for:

- Redness
- Skin breakdown
- Small, inflamed, pus-filled blisters
- Burning sensation at the tube site

Dehydration

Dehydration occurs when there is an imbalance between the amount of water taken into the body and the amount of fluid that is lost. Dehydration means that the body needs more water. Children with dehydration can exhibit a number of different signs, including: increased thirst, dry lips, dry and warm skin, rapid weight loss, weakness, fever and urine that is dark and strong-smelling.

Causes	Prevention and Treatment
Diarrhea	<ul style="list-style-type: none"> Notify your health care professional if your child has vomiting, fever or diarrhea that lasts longer than 24 hours. Record the amount of water and formula that you are giving your child each day and make note of the color and odor of the urine. Ask your child's physician how much extra water you should be giving your child on a daily basis. Extra water can be given through the feeding tube using a syringe or feeding bag.
Vomiting	
Fever	
Excessive sweating or drooling	
Inadequate fluid intake	

1	Good
2	Good
3	Fair
4	Dehydrated
5	Dehydrated
6	Very dehydrated
7	Severely dehydrated

When dehydration is present, urine becomes darker and more concentrated.

Look for:

- Increased thirst
- Dry lips
- Dry and warm skin
- Rapid weight loss
- Weakness
- Fever
- Dark, strong-smelling urine



Navigating Your Doctor Visits

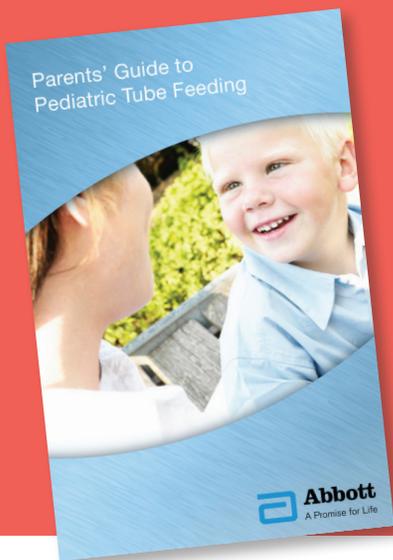
When you're a parent of a tube-fed child, a doctor's visit can seem overwhelming. There are so many issues to discuss in a short amount of time – all while you're attending to your son or daughter. It's easy to forget something important and realize afterward that you didn't get the answers you needed.

One way to simplify things is to think of your appointment as having three stages: before, during and after. Following the easy tips below at each stage can make your visit a lot less stressful – and a lot more productive.

What to bring with you:

This booklet, which includes your:

- Tube Feeding Monitoring Checklist (P. 20-27)
- Medication Record (P. 28-29)
- Notes page (P. 30-31)
- A list of questions and concerns that you want to discuss



Before the visit:

- Review information that you have documented in your Tube Feeding Monitoring Checklist and Medications Record.
- Make a list of questions and concerns that you want to discuss.
- **If you are going to be discussing a problem, be prepared to provide the following information:**
 - A detailed description of the issue, including when and how it began as well as any symptoms
 - What, if anything, you have done to treat the problem
 - Things that have made it better or worse

During the visit:

- Use your list to check off each item as it is addressed.
- Take notes so that you can refer back to them after the visit (Use the Notes section on P. 30-31.).
- Make sure that you provide details/history of any medical conditions your child has that the doctor may not be aware of.
- If you can't follow something that is said, ask the doctor to explain it in a way that you can understand.
- If the doctor suggests a treatment that you are unsure of, communicate this and ask what other treatment options might be available.
- If you are discussing a problem, ask how long it should take to improve and/or resolve after starting the prescribed treatment.
- Ask when and how you should follow up after the visit (phone call, email or office visit).



After the visit:

- If you do not see results from the treatment within the expected time frame, inform your doctor as soon as possible.
- Don't hesitate to call the office if you have questions or concerns.
- Don't be afraid to ask your doctor for a referral when a problem is not resolving or when input from a specialist might be needed.



Tube Feeding Monitoring Checklist

Date: _____

Date:	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
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.	Thurs.	Fri.	Sat.	Sun.
Skin: Redness Drainage Granulation tissue Skin breakdown							



Tube Feeding Monitoring Checklist

Date: _____

Date:	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
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.	Thurs.	Fri.	Sat.	Sun.
Skin: Redness Drainage Granulation tissue Skin breakdown							



Tube Feeding Monitoring Checklist

Date: _____

Date:	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
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.	Thurs.	Fri.	Sat.	Sun.
Skin: Redness Drainage Granulation tissue Skin breakdown							



Tube Feeding Monitoring Checklist

Date: _____

Date:	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
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.	Thurs.	Fri.	Sat.	Sun.
Skin: Redness Drainage Granulation tissue Skin breakdown							



Glossary

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 or all night (or both).

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.

A complete portfolio of products to meet
all of your pediatric tube feeding needs



Use products under medical supervision.

www.NutritionAlly.com

©2014 Abbott Laboratories Inc.
90722/April 2014 LITHO IN USA
www.abbottnutrition.com

Abbott Nutrition
Abbott Laboratories
Columbus, Ohio 43219-3034

 **Abbott**
Nutrition