



# Guide to Percutaneous Endoscopic Tubes (PEG's)

© Rady Children's Hospital, San Diego 2011

Reviewed October 2017

## Table of Content

Introduction .....	i
Important Contact Information .....	1
PEG-Tube & Feeding Information .....	2
Important Facts & When to Call the Doctor.....	4
Anatomy of Digestive System .....	6
Percutaneous Endoscopic Tube (PEG) .....	7
Medication Facts .....	11
Care of Tube and parts .....	20
Daily Skin Care.....	22
Venting and Feeding .....	25
Tube Dislodgement .....	29
Going Home/ Travel Kit .....	32
Medical Glossary .....	36
Problem solving and common questions.....	37
Recommended Reading/Caregiver Support .....	41
Caregivers Notes .....	42

Dear Parents and Caregivers,

As your child prepares to have a Percutaneous Endoscopic Gastrostomy Tube (also called PEG), we realize that you will have many questions about the procedure and how it will affect your child's life. This journal will give you important facts about your child's surgery and care. The journal also reviews all areas of care your child will need following a PEG tube placement.

We believe your child deserves personalized care and you may find that some of your child's care will differ from what is in this journal. It is important to always follow your child's Physicians plan of care.

We hope this journal covers most of your questions and concerns. Our nurses, doctors, occupational therapists and all specialty teams are available to answer any other questions you may have. Do not hesitate to seek further information at any time!

When your child is discharged from the hospital, our Home Care team will help you learn to care for your child at home. There may be a few differences between your hospital routine and your home routine. There may also be some differences between supplies you will use while in the hospital and at home. Your Home Care team will be there to support, guide and instruct you in all areas.

At Rady Children's Hospital, our goal is to work together as a team of surgical, medical, nursing, specialty groups and - most importantly - caregivers and children. We are here to provide you with the highest level of care for your child and ensure that you are fully informed and involved with all areas of care.

Sincerely,

*Tips and Tubes Committee 2014  
Rady Children's Hospital*

## Important Contact Information

If your child's tube falls out on the weekend or outside of office hours, call Rady Children's Hospital at (858) 966-1700. Ask for the on-call GI Physician.

Rady Children's Hospital—San Diego  
3020 Children's Way, San Diego, CA 92123

Emergency Department Number: (858) 966-8005

Rady Children's Gastroenterology (GI) Services: (858) 966-4003

Rady Children's Gastroenterology (GI) Clinic & Nurse Specialist: (858) 966-1700 x. 5606

Rady Children's Hospital - Main Number: (858) 966-1700

Rady Children's Occupational/Physical Therapy: (858) 966-5829

Rady Children's Referral Service: (800) 788-9029 or (858) 966-4096

Rady Children's Outpatient Pharmacy: (858) 966-4060

Rady Children's Home Care: (858) 966-4941

Rady Children's Hospital Website: [www.RCHSD.org](http://www.RCHSD.org)

GI Physician's Name: \_\_\_\_\_ Phone # \_\_\_\_\_

Primary Care Physician (PCP) Phone #: \_\_\_\_\_

Home Pharmacy Phone #: \_\_\_\_\_

Home Care Phone #: \_\_\_\_\_

Medical Insurance Phone # \_\_\_\_\_

Notes

---

---

---

## My Child's PEG-Tube Information

Please follow the time guides below as to when you can place an emergency tube. It is important that you contact your child's GI Physician before inserting an emergency tube if your child has had the tube for less than 12 weeks. Always contact your child's GI Physician or Nurse Specialist if you have any concerns regarding the fit of your child's tube.

Date of Tube placement: \_\_\_\_\_

Date Emergency Red Robin Tube can be inserted (*6 weeks after placement*): \_\_\_\_\_

Date Emergency G-Tube can be inserted (*6 weeks after placement*): \_\_\_\_\_

Size of PEG Tube: \_\_\_\_\_ French \_\_\_\_\_ cm

Size of red robin tube: \_\_\_\_\_ French

Length Red Robin Tube to be inserted: \_\_\_\_\_ inches

Day of week extension tube to be changed: \_\_\_\_\_

### Notes

---

---

---

## My Child's Feeding Schedule

Only feeding formulas and medications that have been ordered by your child's Physician, Dietician or Occupational Therapist should be given through the PEG tube.

Type of feed: \_\_\_\_\_

Special formula preparation Recipe: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Day-time feeding schedule: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Night-time feeding schedule: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Daytime: \_\_\_\_\_ ml per hour (pump program)

Overnight: \_\_\_\_\_ ml per hour (pump program)

Notes

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Important Facts

1. If your child develops breathing difficulties during or immediately after feeding, ***stop the feeding immediately.*** Attach a 60 ml syringe to the extension tube or PEG tube and place at a lower level than the stomach allowing gravity to empty stomach contents (see Pg. 25). ***Call 9-1-1 immediately if breathing difficulties continue.***
2. ***Always*** keep your child's travel kit with them
3. If the original tube falls out **during the first 6 weeks** after surgery, cover the stoma (hole) with gauze, call your child's GI Physician and take your child to the Emergency Department **immediately.** (***take your travel kit with you.***)
4. If your child's tube falls out **more than 6 weeks** after surgery call your child's GI Physician. If you have been trained to insert a red robin tube or a mic-key button tube they may ask you to insert a new one. Do not force the tube into the stoma. Once tube is inserted, your child's GI Physician will give you follow up instructions.
5. ***Never*** give feeds or medications through a red robin tube (this is a temporary tube). ***Never*** give feeds or medication through an emergently inserted tube if it is less than 12 weeks after placement unless instructed to do so by your child's GI Physician.
6. If your child's tube feels loose or there is increased leaking of fluid around tube call your child's GI Physician for follow up.
7. Only feeding formulas and medications that have been ordered by you child's Physician, Dietician or Occupational Therapist should be given through the PEG tube.
8. Rotate PEG tube 1/4 to 1/2 circle once a day ONLY if instructed to do so by your child's GI Physician.
9. Remove all extension tubes after every feed and clean thoroughly.
10. If the PEG tube falls out it is important that a new tube is inserted **as soon as possible.** (*Follow instructions 3 and 4 on this page.*)

## When to Call Your Child's Doctor

1. If the skin around the tube site feels warmer than normal, looks red or is painful to touch.
2. If there is fresh bleeding or puffy red tissue around your child's tube site.
3. If there is increased leaking around the tube site.
4. If there is yellow or green drainage from the tube site that has a foul odor.
5. If your child has vomiting, retching or diarrhea.
6. If the feeding tube becomes blocked and you cannot remove the blockage.
7. If your child has a fever over 101 degrees Fahrenheit, contact your child's Primary Care Physician (PCP) first.
8. If there are any bloody secretions in the PEG tube tubing.
9. If your child's stomach remains full and swollen after venting, and he/she appears to have discomfort or pain.
10. If your child's tube falls out less than 12 weeks after insertion.
11. If you have difficulty inserting a replacement tube more than 12 weeks after insertion.

---

Complications with your child's newly placed PEG-tube can be discussed with your child's Primary Care Physician (PCP), the GI clinic, or your child's GI Physician. Once your child's g-tube has been in place for a while, your child's PCP or the GI clinic will be managing your child's care. Please note that the Nurse Practitioners or GI Clinic Nurses will be happy to help you address any question or concerns.

To reach your child's Physician or Surgeon:  
**(858) 966-1700, Ext. 0**

and ask for your child's physician or surgeon, or the GI physician or surgeon on call.

### GI Services

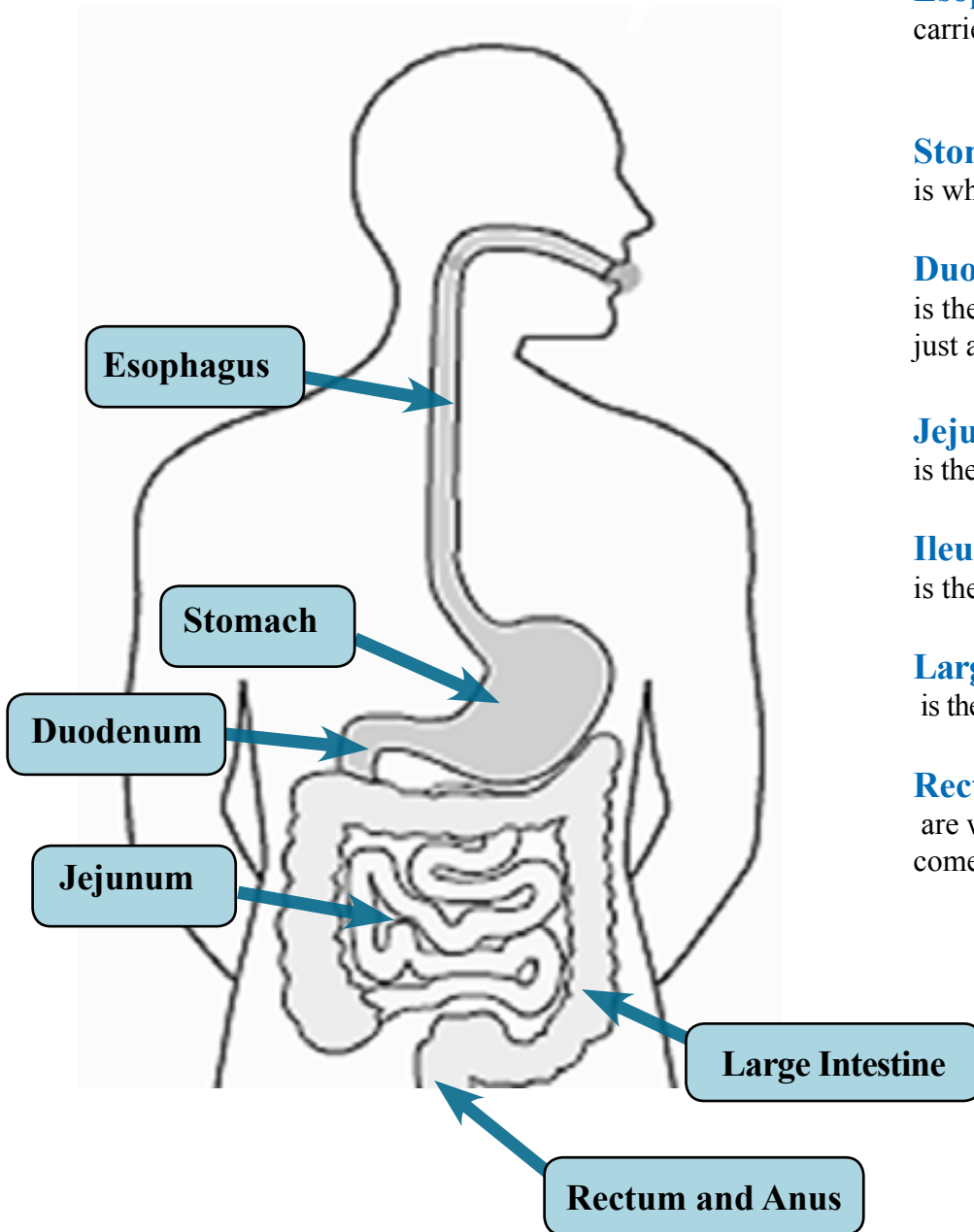
Main Clinic Phone Number: **(858) 966-4003**

### GI Clinic & Nurse Specialist Line

Nurse Specialist Phone Number: **(858) 966-1700, Ext. 5606**



## Anatomy of the Digestive System



### **Esophagus:**

carries food from the mouth to the stomach.

### **Stomach:**

is where food begins the process of digesting.

### **Duodenum:**

is the first part of the small intestines and lies just after the stomach.

### **Jejunum:**

is the middle of the small intestine.

### **Ileum:**

is the last part of the small intestine.

### **Large Intestine:**

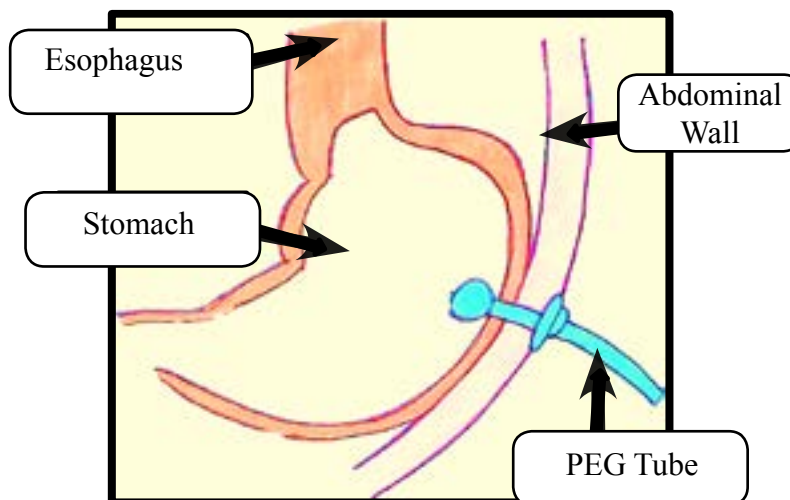
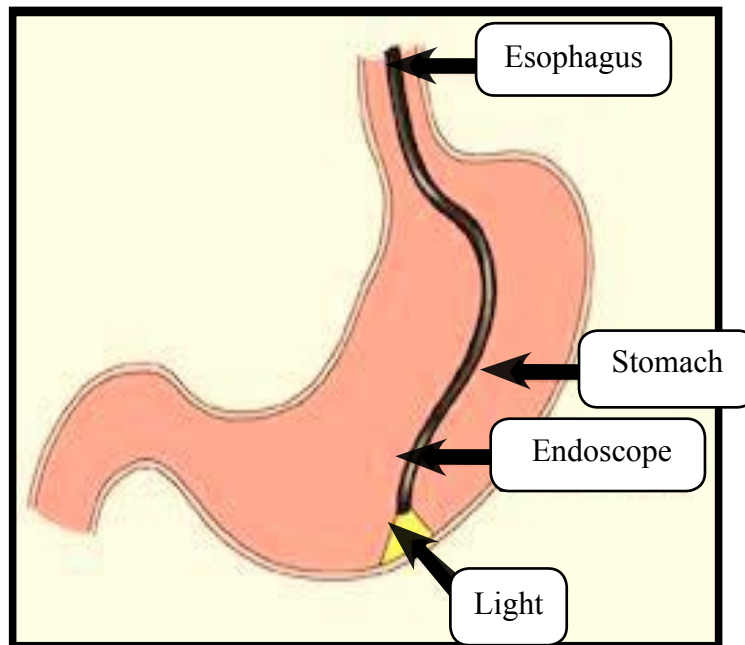
is the final part of intestine.

### **Rectum and Anus:**

are where the waste products from the body come out.

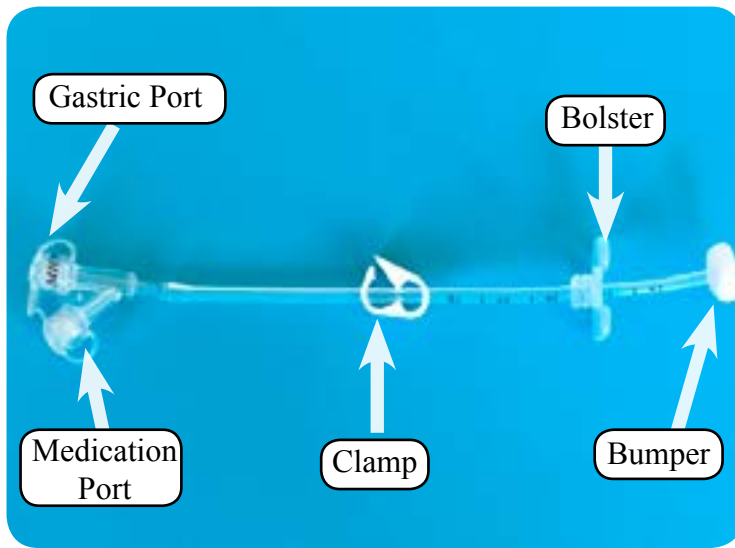
## Percutaneous Endoscopic Gastrostomy Tube (PEG)

Percutaneous Endoscopic Gastric Tube (PEG) placement is normally done under general anesthesia here at Rady Children's Hospital. A small tube with a light (endoscope) is passed down the esophagus and into the stomach. The light shines through the stomach wall and allows the Physician to accurately place a small hole in the stomach wall. The PEG tube will then be placed through this small hole into the stomach and secured in place with a soft dome (bumper) resting against the inside stomach wall and a soft disk (bolster) resting outside against the tummy wall.



## Percutaneous Endoscopic Gastrostomy Tube (PEG)

The PEG tube has two ports, a gastric port for feeds going into the stomach and a medication port for giving medications. This tube also has a clamp attached which allows you to clamp the tube and stop milk from leaking if the ports open accidentally. An extension tube may be used with this tube if needed to give a little extra length.



### Important facts about this Tube

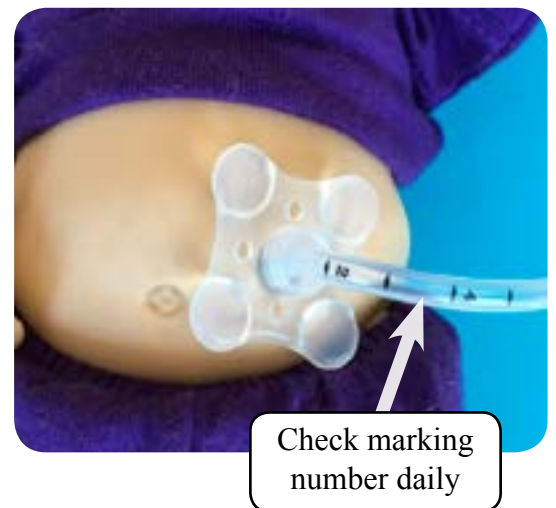
This tube has a small portion of tubing permanently attached which cannot be removed. To prevent the tube from blocking it is important that the tube is flushed with water after every bolus feed or every 3 to 4 hours during the day if you child is on continuous feeding.

Flush amounts:

2-3ml for infants/babies

5 -10 ml for older children.

**It is important that you check the markings on this tube daily to ensure that the tube has not changed position.**



## Attaching/removing PEG feeding bag and tubing.

### To Attach the feeding tube/bag:

1. Ensure all ports are closed



2. Close clamp of PEG Tube



3. Attach feeding tube into gastric (feeding port), gently twist to secure. Open Clamp.



### To Remove feeding tube/bag:

1. Close clamp of PEG Tube



2. Gently twist and remove tubing from feeding port. Close all ports.



## PEG Tubes

### Attaching & Removing medication/venting syringe and feed tubing.

Non-ENFIT PEG tubes may need an extra connector to attach the feed tubing, medication syringes and venting syringes securely. Gently twist the white connector in a clockwise motion to attach and a counterclockwise motion to remove.

#### Attaching Medication Syringe:



#### Attaching Feed Tubing:

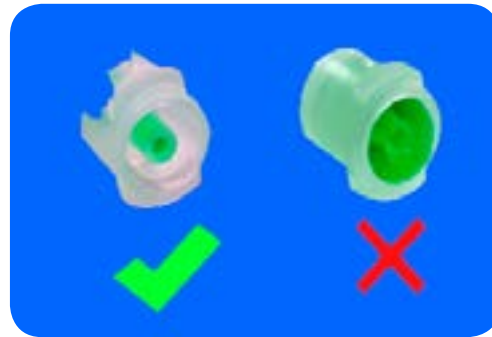


#### Attaching Venting Syringe:



## Drawing up medications

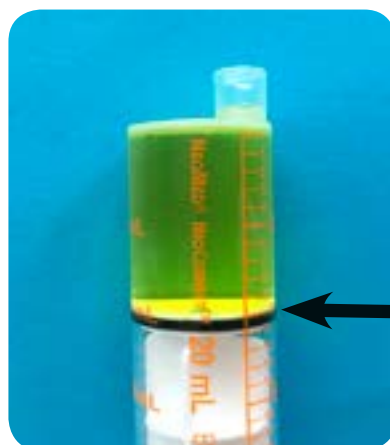
If using a 1ml, 3ml or 6ml syringe only the inner portion of the tip is filled with medication.



If using a larger syringe the tip is completely empty of medication.



Draw medication up to the inner side (side nearest medication) of the black plunger.



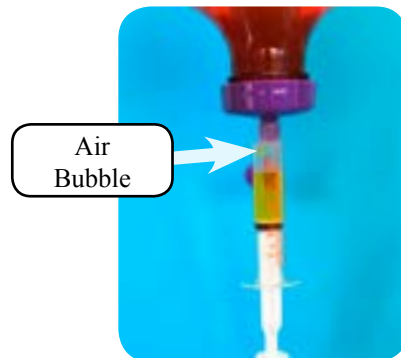
Medication  
Guide Line

## Drawing up medications with a bottle cap attachment

Remove original bottle cap and gently screw the medication cap to medication bottle. Make sure the cap is securely attached.



Attach medication syringe to bottle cap. Turn the bottle upside down and draw medication into the syringe. If an air bubble appears in syringe move bubble to upper part of syringe and push it back into the bottle.



Turn bottle right way up and remove syringe. Place top on medication cap.

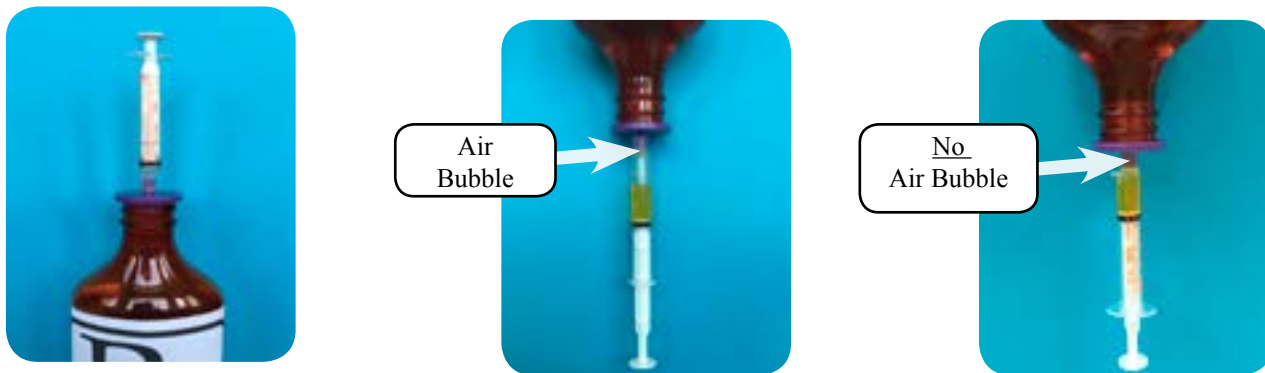


## Drawing up medications with a bottle cap attachment

Remove original bottle cap and **gently** attach the medication cap to medication bottle. Make sure the cap is securely attached.



Attach medication syringe to bottle cap. Turn the bottle upside down and draw medication into the syringe. If an air bubble appears in syringe move bubble to upper part of syringe and push it back into the bottle.



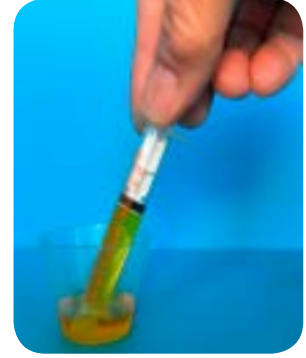
Turn bottle right way up and remove syringe. Remove medication cap and replace original bottle cap.





## Drawing up medications from a medication cup

Pour medication into medication cup. Insert tip of syringe into cup and pull out required amount of medication.



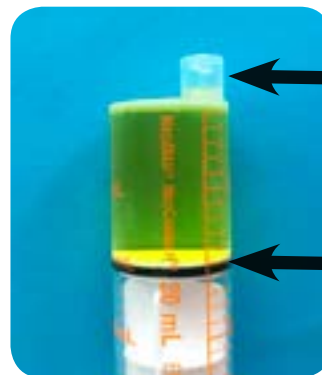
Remove syringe and gently tap syringe to remove any air bubbles. Wipe the syringe with a clean cloth to remove any excess medication.



**Important:** Medication is measured to the inner side of black plunger. 1ml, 3ml and 6ml syringes should only have the inner part of the tip filled with medication. Larger syringes should have the tip completely empty of medication.



Smaller syringes only inner part of tip with medication



Larger Syringes tip empty of medication

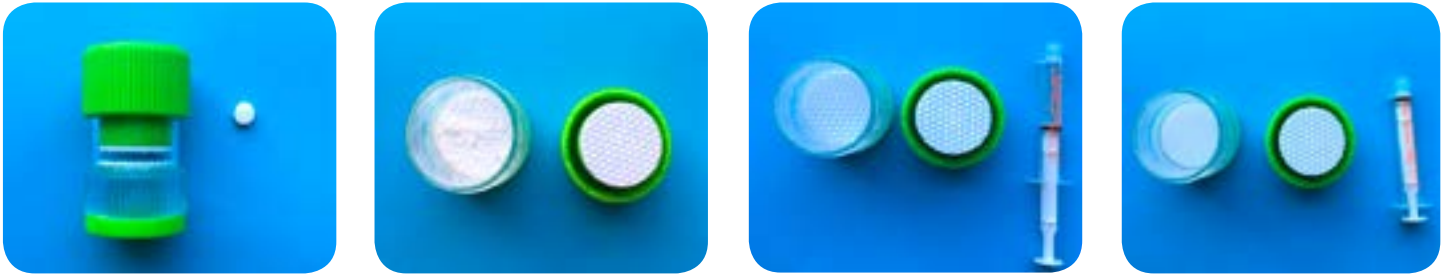
Medication Guide Line

## How to administer crushed medication

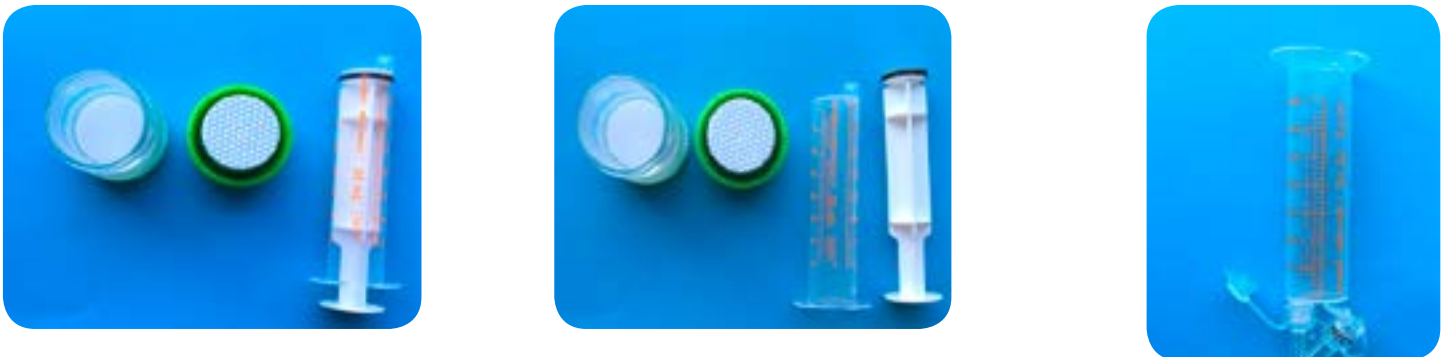
**Check with Pharmacist before crushing any medication tablets.**

Crush tablet with a pill crusher until it becomes a fine powder.

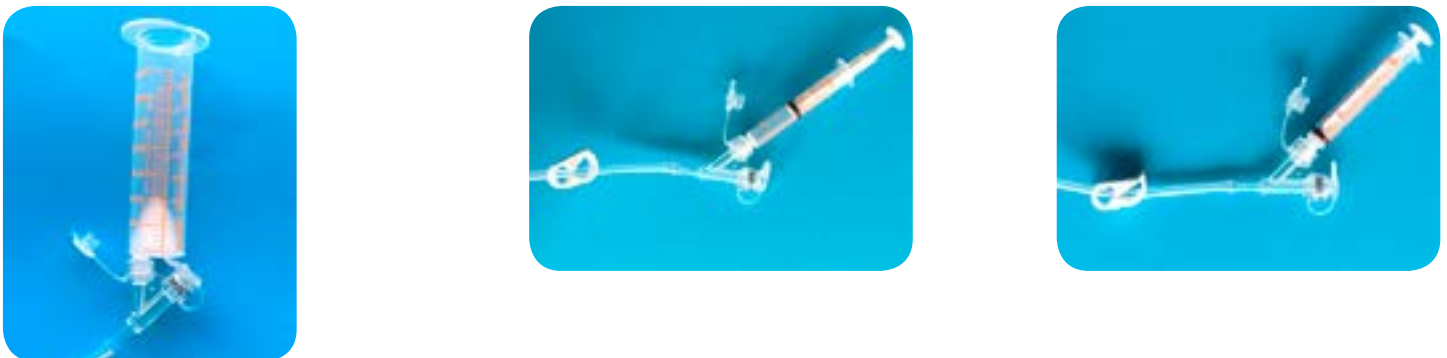
Add water (*2-5ml for infants, 5-10ml for older children*) to powder and mix well until powder is dissolved.



Pull plunger out of 35ml or 60ml syringe. Attach syringe to medication port of g-tube/extension tube (like a funnel).



Pour dissolved medication into the syringe and allow it to flow into tube by gravity. Flush the tube with water until completely clear of ALL medication..



## Giving Medications through ENFIT PEG Tube

Medications should be given through the **medication port** on the PEG Tube. It is the smaller port located to the side of the feeding port.

1. Check placement (pg 24). Clamp extension tube. Draw water into a 6 ml or 12 ml syringe. Attach syringe to medication port. Unclamp tube and flush with water to clear. Re-clamp tube and remove syringe.



2. Attach medication syringe to medicine port. Unclamp tube and gently push medication into tube. Re-clamp tube and remove syringe.



3. Draw water into a 6 ml or 12 ml syringe and attach to medication port. Unclamp tube and flush with water until the tube is clear. Clamp extension tube and remove syringe.



**Important:** It is important that you flush the tube with water before and after EACH medication. Use 1 to 3 ml for infants, and 2 to 5 ml for children.

## Giving Medications through Non-ENFIT PEG Tube

Medications should be given through the **medication port** on the PEG Tube. It is the smaller port located to the side of the feeding port.

1. Check placement (pg 24). Clamp extension tube. Draw water into a 5ml or 10 ml syringe, attach connector to syringe. Attach syringe to medication port. Unclamp tube and flush with water to clear. Re-clamp tube and remove syringe and connector.



2. Attach medication syringe and connector to medicine port and unclamp tube. Gently push medication into tube. Re-clamp tube and remove syringe. **Leave connector attached!**



3. Draw more water into a 5 or 10 ml syringe and attach to medication port. Unclamp tube and flush with water until the tube is clear. Clamp extension tube and remove syringe and connector.



**Important:** It is important that you flush the tube with water before and after EACH medication. Use 1 to 3 ml for infants, and 2 to 5 ml for children.

## Important Medication Facts

It is important to understand the different types of medications your child is prescribed. Some medications need to be taken with food while others may not be given with food because food changes the effect of the medication.

Check with your child's Physician and/or Pharmacist regarding special instructions for your child's medications. Always check with your Physician and Pharmacist before starting your child on any new medications to ensure there are no potential problems. Liquid medication is the only recommended type of medication to be given via PEG tubes

Some children have capsules or tablets prescribed. Check with your child's Physician and Pharmacist to ensure that you can alter the way to give these medications.

<b><u>Capsule: slow release beads</u></b>	These are <u>NOT RECOMMENDED</u> for PEG tubes. Ask your child's doctor for a liquid form of medication.
<b><u>Capsule: soft gelatin</u></b>	These are NOT RECOMMENDED for PEG tubes. Ask your child's doctor for a liquid form of medication
<b><u>Capsule: powder inside</u></b>	Remove the outer case and empty powder into a small dish. Mix the powder with water until all the powder has dissolved (2-5 ml for infants and 5-10 ml for older children). Remove plunger from 20ml syringe and connect to g-tube/extension tube medication port. Pour dissolved medication syringe barrel, like a funnel. (pg 16). Flush the tube clear with water after giving the medication.
<b><u>Tablet</u></b>	<b><u>Check with your child's Pharmacist or Physician before crushing any medication.</u></b> Crush the tablet into a fine powder with a pill crusher. Mix the powder with water until all the powder has dissolved (2-5 ml for infants and 5-10 ml for older children). Remove plunger from 20ml syringe and connect to the g-tube/extension tube medication port. Pour dissolved medication into the syringe barrel, like a funnel (pg 16). Flush the tube clear with water after giving the medication.

## Important Medication Facts continued ...

The following are guidelines to help you when your child needs to be given medication in a specific way.

Flush the tubing with water between each medication, making sure the tubing is clear from the previous medication before giving the next one.

<p><b><u>To be given with food:</u></b></p>	<p>The medication can be given at any time during your child's feed. Bolus feeds can be adjusted a little to fit in with the times of the medication. If your child is older and can take food by mouth, you can always give him/her a little snack to take with the medication.</p>
<p><b><u>To be given on an empty stomach</u></b></p>	<p><u>Bolus Feeds:-</u> The best time to give medications is usually half way between feeding times. Try pulling back stomach secretions with a syringe. Give medication when you get the smallest amount of secretions returned.</p> <p><u>Continual Feeds:-</u> Stop the feeds for 15 - 20 minutes to allow the stomach to empty. Give medications and then leave feeds off for another 15 -20 minutes to allow the medication to be absorbed. If your child is on a strict diet you can increase his/her feed a little over the next hour to catch up on volume. Discuss with your child's Physician the best way to do this.</p>

### Understanding Units of Measurement:

**1 cc = 1 ml**

**1 fl.oz = 30 ml**

**1 cup = 8 oz = 240 ml**

## Preventing Tube Blockage

**Remember:** Your child's tube need to be flushed with water at regular intervals to keep it in good working order.

It is important that you flush your child's tube with water after every bolus feeding, as well as before and after every medication. If your child is on a continual feeding program, then flush the tube at least every 4 hours during the day (normally while changing your child's milk).

**Infants**, 2 to 5 ml of water should be used to flush the tubes clear.

**Older children**, 5 to 10 ml of water should be used to flush the tubes clear.

Check with your child's nurse how much water is needed to flush your child's tube.

A **12 inch** extension tube requires approximately 3 ml to clear.

A **24 inch** extension tube requires approximately 5 ml to clear.

A **PEG Tube** requires approximately 3 -5 ml to clear.

### Helpful Tips

- Only give formula and food preparations that have been prescribed by your child's Physician, dietician or feeding specialist.
- Only give medications that have been cleared by your child's Physician. Make sure the medication is given in the form that was prescribed by your child's Physician.
- The water you use to prepare your child's formula can also be used to flush the tube.

## Care of Equipment

### Formula Container and Syringes:

1. After each use, wash well with warm water and a little dish soap.
2. Rinse well with clear warm water to ensure all soap is removed.
3. Air dry on a clean towel.
4. When the container and syringe are completely dry, store them in a clean and covered container.

### Feeding Bag and Tubing:

1. After each use, wash with warm water.
2. You may need to squeeze the tubing and bag to clear out all the milk.
3. Rinse thoroughly with clean warm water.
4. Air dry and store in a clean covered container.

### How frequently to change equipment:

Your medical insurance coverage will determine how frequently you will change out your feeding bags and extension tubes. Please check with your Home Care team and your insurance provider to determine what supplies will be available to you.

Feeding bags can be used for 24 hours, or sometimes longer. It is important that your feeding bags are kept as clean as possible; therefore, thorough cleaning between feeds is advised. Many insurance companies will allow these bags to be discarded and changed every day.

The extension tubes can be used for a week, or sometimes longer. It is important that you remove your child's extension tube and clean it thoroughly between feeds. Your insurance company will determine how frequently you will be able to change them. However, if at any point in time the tube starts to leak or the tube becomes difficult to clean, it is advisable that you discard and change it.

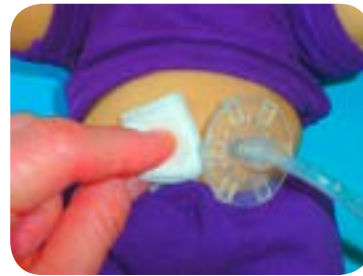


## Daily Skin Care

### Important:

- Always wash your hands before touching your child's PEG tube!
- You may be instructed by your child's GI Physician to turn the PEG tube 1/4 to 1/2 rotation once a day to prevent the tube from sticking.

1. Soap and warm water may be used to clean the area once stoma site is healed. Be sure that soap residual is removed with fresh water to avoid drying out your child's skin. Gently pat the area around tube dry with gauze or a soft clean cloth.



2. Cotton tip applicators (Q-Tips) can be used to clean under and around the tube to give you better access.



3. If the tube remains slightly loose or the site is showing signs of irritation from rubbing, then a 2 x 2 inch piece of gauze can be placed between the tube and the skin to prevent rubbing.



## Skin Care Problems

It is important that you check your child's g-tube site daily for any changes including redness, puffiness, breaks in skin, bleeding or any discharge that has a foul odor.

<p><u>Redness or irritation around your child's PEG tube site:</u> This can be caused by leakage of fluid around the tube site, tape irritation, infection or the tube being pulled by your child.</p>	<ul style="list-style-type: none"> <li>* Keep skin around g-tube clean and dry</li> <li>* A 2x2 inch piece of gauze may be placed between the skin and the tube. Change the gauze with every diaper change or anytime it gets wet.</li> <li>* Try and expose as much of the site to air when possible.</li> <li>* Take care not to over clean the site and damage the the fragile skin (once or twice a day is enough!)</li> <li>* Call your doctor if there is any unusual redness, the site feels warmer than usual or there is any smelly discharge (these are signs of infection).</li> <li>* Barrier wipes and creams may be used if advised to do so by your child's GI Physician or GI Nurse Specialist.</li> </ul>
<p><u>Leaking around PEG tube:</u> This can be caused by a leak in the balloon or your child pulling on the tube causing the stoma to become larger which can cause leaking</p>	<ul style="list-style-type: none"> <li>* Remove extension tube after each feed.</li> <li>* Hide the tubing from your child under clothing to prevent his/her from playing with it.</li> <li>* Vent your child's tube before and after every feed and any time his/her tummy looks full.</li> </ul>
<p><u>Extra skin growth around PEG tube site (Granulation):</u> This can be caused by moisture and constant movement of the the tube against the skin.</p>	<ul style="list-style-type: none"> <li>* Place a 2x2 inch piece of gauze between skin and tube. Change gauze with every diaper change and when it gets wet.</li> <li>* If the skin continues to grow, contact the GI Clinic to schedule a nurse's visit for further assessment.</li> <li>* Contact your child's doctor for further advice on treatment and care.</li> </ul>

## Checking Placement of Tube

It is advised that you check your child's g-tube to make sure it is in the correct position before you give feeds or medication. This is particularly important if your child is active and tugging on tubing.

**Always** check the placement of a newly inserted g-tube before giving feeds or medication.

**1. Gravity:** Remove the plunger from a 35ml or 60ml syringe. Attach the syringe to your child's clamped g-tube or extension tube. Unclamp tube and place syringe lower than the stomach. Observe for gastric (stomach) secretions.

**2. Aspirate:** Attach a 35ml or 60ml syringe to the end of your child's g-tube or extension tube and pull the plunger back gently checking for gastric (stomach) secretions.



## Venting via the PEG Tube

Children who have a PEG tube may occasionally need help with burping. Venting the PEG tube will allow your child to burp. Every child is different and venting should be adjusted to your child's needs. Venting need only be carried out if your child appears uncomfortable.

1. Remove plunger from a 60 ml syringe and attach to the PEG tube extension or venting tube.
2. Place the syringe at a higher level than your child's stomach.
3. Vent the tube until all gas has been released from your child's stomach or until they feel more comfortable



### **Important:**

If your child's stomach suddenly distends (gets bigger) and your child is in obvious distress after venting, remove plunger from 60ml syringe and attach to extension/decompression tube. Empty your child's stomach contents into a bowl by placing syringe at a lower level than stomach. Be sure to call your child's physician or surgeon as soon as possible!



## Types of Feeding

### Continual Feeds:

Based on your physician's recommendation, your child may be on continuous feeds for the full 24 hours or strictly overnight. Continuous feeds are always delivered by a pump. Home Care services will deliver and teach you how to use your pump.

**Important:** It is important to stop continuous feeds every 3-4 hours during the day to clean the feeding bag and vent the PEG tube

### Bolus Feeds:

A bolus feed is when your child is given a set amount of feed over a set period of time as ordered by your child's Physician or Dietician. Bolus feeds may be given by pump or gravity feeding depending on length of time feeds have to be given over:

### Pump feeding:

Your child's physician may want you to give feeds over the period of an hour or two. In this case the feeds will need to be delivered by pump. Your nurse will show you how to calculate the amount of milk and time to give the pump before you are discharged to leave the hospital.

### Gravity feeding:

Your child's physician may want you to give feeds over a short period of time (between 20 to 30 minutes). Gravity feeding is completed using a 35ml or 60 ml syringe that is attached to your child's extension tube. The speed of the feeding can be adjusted depending on the height that the syringe is placed above the stomach.

**Important:** Flush your child's PEG tube and extension tube with water after every bolus feed or every 3-4 hours if your child is on continual feeding.

Infants ..... flush 2-5ml of water  
Older Children ... flush 5-10ml of water

## Feedings

### Pump Feeding

1. Prime feeding tube and pump.
2. Clamp the extension tube shut.
3. Attach the extension tube to the feeding port.
4. Check placement of tube (pg 24)
5. Attach the main feeding tube to the feeding port of the extension tube.
6. Unclamp extension tube.
7. Start feeds at ordered rate.
8. Once feed complete clamp extension tube and remove main feeding tube.
9. Vent the tube while cleaning the bag and adding milk.
10. Flush extension tube with water to clear.
11. Remove extension tube and clean. Repeat all steps.



### Gravity Feeding

Completed over 20 to 30 minutes.

1. Prepare feed.
2. Clamp extension tube.
3. Attach extension tube to feeding port.
4. Check for placement of tube (pg 24).
5. Remove plunger from 60 ml syringe
6. Attach 60 ml syringe to feeding port .
7. Unclamp the extension tube and
8. Slowly raise the syringe above the level of the stomach.
9. Control the flow of milk by raising or lowering the syringe level.
10. Vent until all stomach gas has been removed.
11. Flush with water to clear tube.
12. Remove extension tube and clean.
13. Close feeding port.



Keep child's head  
above level of stomach

**Remember:** The higher you hold the syringe, the faster the feed will flow. If you feed your child too quickly, it may cause your child to vomit or experience discomfort.

## Positioning: Daytime & Bolus Feeding

Even though your child is being fed by a PEG tube, it is important to provide your child with oral stimulation and the social interaction that surrounds mealtime.

### Feeding positions for infants under 6 months:

#### Suggested Positions

1. Cradle held
2. Infant Seat
3. Car Seat
4. Wedge
5. A Boppy



### Feeding positions for infants 6 months and older:

Typically mealtimes become more interactive as your child gets older and they start learning feeding skills. We encourage you to have your child supported in a highchair to give your child opportunities to interact with the family during mealtimes, and start exploring and imitating feeding behaviors.



## Positioning: Nighttime Feeding

Your child may need to have continuous feeds overnight. The recommended position is usually your child lying on his or her back or side. Blankets, toys and crib bumpers should not be placed in or around your child's crib. In special situations your doctor may suggest that you raise the head of your child's crib or bed. Always follow your child's Physician/Surgeons recommendations.

***Infants should not lay on their stomach unless you are instructed to do so by their doctor.***



## Tube Dislodgement! What to do if your child's tube falls out.

There may be an occasion where your child's PEG tube may fall out. In most cases this happens accidentally while your child is playing; on other occasions it is due to the sutures or balloon becoming dislodged or deflated. A few simple tips will help you to reduce the chances of your child's tube falling out:

1. Remove the extension tube and feeding tubing when your child is not being fed.
2. Keep the tubing secure and away from your child by hiding it under his or her clothing (e.g. onesies).
3. Do not allow your child to pull or play with the tubing.
4. **Important:** *Keep your child's travel kit with you at all times!*

### In the event that your child's tube does fall out:

1. Do not panic! The stoma will start to shrink after the tube falls out, but you still have time to get things in place.
2. Check how many weeks after tube placement your child is.
  - If child is **less than 6 weeks** after tube placement cover stoma with gauze, call GI Physician immediately and go to Emergency Department for a new tube (take travel kit with you)
  - If child is **more than 6 weeks** after tube placement, and you have been trained, you can place a Red Robin Tube or a mic-key button tube (pg. 30/31) Call GI Physician for follow up instructions.

### **Important:**

**Never** force a tube into the stoma (hole)

**Never** give any feeds or medications through a red robin tube.

**Always** Call your child's GI Physician for follow up instructions if your child's PEG falls out.

**Always** take your travel kit, to the Emergency Department with you.

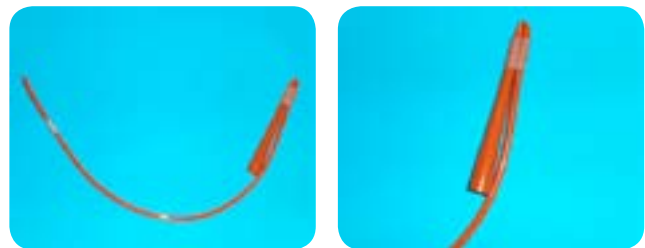


## Inserting an Emergency Red Robin Tube

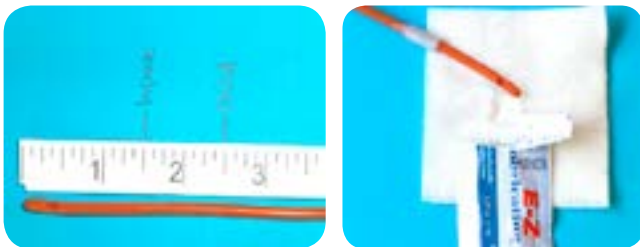
If the PEG tube falls out more than **6 weeks after tube placement** and you have been trained, you can gently insert a red robin tube. Once the tube is inserted, call your child's GI Physician, and then go to the Emergency Department for a new tube. If you feel any resistance while trying to insert the red robin tube: stop, remove the tube and place a gauze swab over stoma. Go to the Emergency Department (**remember to take your child's travel kit**).

**Important:** *Never force the red robin tube into the stoma (hole).  
Never give any feeds or medications through red robin tube!*

1. Cover the stoma with gauze until you collect supplies (gauze, tape, lubrication, red robin tube).
2. Fold the **open, larger end** of the tube back onto itself and tape in position.



3. Measure 1.5 inches for infants, or 2 to 3 inches for children, from the **tip** of the red robin tube. Run tape around tube. Lubricate the tip of the tube.



4. Gently insert tip into stoma (hole) until you reach the tape in step 3. Insert at a **90 degree angle** to your child's tummy. **Stop and remove** tube if any resistance is met.



5. Secure the new red robin tube in place by applying tape in a cross-over style. Secure with more tape as needed.



6. Check the tube is in correct place by removing tape from open end, Place tube at lower level than stomach and watch for stomach secretions. Re-tape open end of tube.



## Replacing a Mic-Key Low Profile G-Tube

If the PEG tube falls out more than **6 weeks after tube placement**, and you have been trained, you can place a new mic-key low profile g-tube. If you feel any resistance while trying to insert the tube: stop, remove the tube and place a gauze swab over stoma. Call your child's GI Physician and go to the Emergency Department (*remember to take your child's travel kit*).

**Important: Never force tube into the stoma (hole).**

1. Collect all your supplies. Put gauze swabs over the hole and tape in place. Pull 3 to 5ml of sterile water into 5 ml syringe.



2. Take new mic-key button tube and check the balloon is intact. Place syringe with sterile water onto balloon port. Gently push water until you see balloon inflate. Remove water from balloon. Keep syringe attached

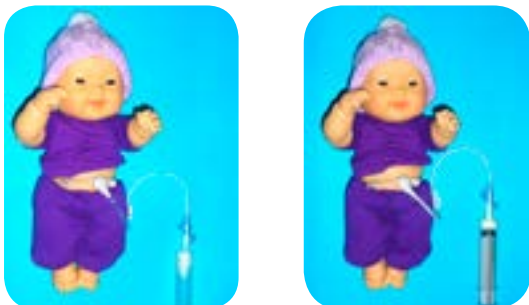


3. Place some lubrication on a swab and dip the tip of the mic-key button into the lubrication. Place child on their back and expose belly. Gently push tube into stoma at a **90 degree angle** to the tummy.

4. Slowly inflate balloon with sterile water. Remove syringe from balloon port



5. Check the tube is in the correct place by watching for stomach secretions from tube.



**Important:**

If it is less than 12 weeks after tube placement:

- \* Call GI Physician for follow up instructions
- \* **Never** give feed or medication through the new tube until your child's GI Physician has given you permission to do so.

## Going Home

Before your child is discharged home it is advised that you spend as much time as possible at the hospital to become familiar and confident with all areas of your child's PEG tube care.

The bedside nurses will let you practice on our PEG tube doll to make sure that you have training in all areas of care needed for your child's tube. Before discharge, the nurses will expect you to carry out the majority of your child's tube care.

Our goal is to make sure that you feel comfortable, and confident with your child and their new tube before you take him/her home.

### **Home Care and Equipment:**

Before discharge someone from the Home Care team will meet with you to go over all aspects of the care you will receive in the community. They will make sure that you have all the supplies you will need and they will arrange for the feeding pump and equipment to be delivered to you. Follow up meetings with a Home Care Nurse will also be made to match with your discharge date.

### **Occupational Therapy:**

Before discharge our Occupational Therapist may meet with you on a regular basis to discuss and practice exercises that you can carry out with your child to help his/her progress to oral feedings at your child's skill level. Our Therapists will also make arrangements for you to come back to one of their clinics for follow up and support.

### **Primary Care and Specialty Clinic Follow-Up Appointments:**

Before discharge, we will ask you to make an appointment with your child's primary care physician. We strongly suggest that your child's first follow-up appointment is held within 24 hours from discharge. A copy of your child's medical record will be sent to his or her primary care physician.

Your may be asked to make your child's specialty clinic appointments prior to your child's discharge from the hospital. We want to ensure that all areas of your child's care is followed up on.

## Parents' Travel Kit

On discharge you will be given a travel kit by the bedside Nurse. Please keep this kit with your child at all times. When you use an item from your travel kit, be sure to replace that item to ensure your kit is fully stocked at all times.

### List of Contents:

- Gauze sponges
- Medical tape
- Lubricating gel
- Bottle sterile water
- 5 ml slip tip syringe
- 30 ml/60 ml slip-tip syringe
- Red robin Tube (in package)
- Tape measure
- New mic-key button tube (in package)
- Mic-key extension tube (12 inches)
- Transition Connector



### Parent to supply:

- Small hand sanitizer
- Small supply of wipes or a wash cloth



### Travel Instruction Cards:

Carry the travel instruction cards with you at all times:

- Inserting a Red Robin Tube
- Inserting a Mic-Key Button
- Important Contact Information
- Important G-Tube Information



### Replacement G-Tube:

You may also carry the new g-tube in its original packaging along with your travel kit.

**Tip:** - prepare Red Robin tube ready for insertion and place in a baggie.  
(see pg. 30)



## Financial Resources

### Insurance

#### Private Insurance

The Member Services number on the back of your insurance card will be helpful for you in determining your benefits for outpatient care, home equipment, supplies and home health (visits from a nurse or shift nursing in which a nurse cares for your child in your home for eight hours or more per day). The amount of benefit coverage will vary from plan-to-plan. Your discharge planner can help you with this information since she has already been discussing your child with a representative from the insurance company. The financial counselors at Rady Children's can also help you with any questions you may have about insurance and your child's stay. The medical unit secretary can help you contact your financial counselor.

#### Medi-Cal

If your family's income is within certain guidelines you may be eligible for Medi-Cal, which provides families with financial assistance for regular check-ups and special medical care. If you are applying for Medi-Cal, contact a financial counselor at Rady Children's. The medical unit secretary can help you contact your financial counselor. If your child currently has Medi-Cal, contact your Medi-Cal representative about current eligibility. Your discharge planner will discuss what the Medi-Cal plan will cover for outpatient care, home equipment, supplies and home health visits (these are visits in which a nurse cares for your child in your home for a set amount of time during the day as dictated by your medical coverage)

#### California Children's Services (CCS)

CCS is a statewide, tax-supported program for specialized medical care and rehabilitation. Children who have a medically eligible diagnosis may receive financial assistance for medical expenses through CCS. A family may be eligible for both Medi-Cal and CCS. A child who is covered by private insurance may also be eligible for CCS for both the inpatient stay and for outpatient care, equipment and supplies. CCS can be helpful when there is need for services that are not covered by your insurance plan. There are financial criteria for the family that your financial counselor can assist you with. Your discharge planner will discuss your child's eligibility and will make the referral to CCS during the inpatient stay of your child if they qualify.

#### Supplemental Security Income (SSI)

If your child has a disability that will last more than one year, you may receive a monthly income. Both the amount received and eligibility are dependent on family income. Families with a wage earner and private insurance may still be eligible. For more information about SSI, call (800) 772-1213.

## Financial Assistance

**In Home Support Services (IHSS):** Children who require special help for their care at home and who are also receiving SSI may also be eligible for IHSS. You may use the money to help care for your child. For more information, you can call IHSS at (866) 351-7722.

**W.I.C. (Women, Infants, Children):** This is program that provides food supplements to pregnant and/or breast feeding women and children at nutritional risk under the age of 5. There is an income guideline that must be met. WIC will also cover many specialty formulas that your child may require. To learn more about WIC services, call (800) 500-6411.

**Anderson Dental Center Endowment:** The endowment is dedicated to enhancing dental care for children with disabilities, special needs and early childhood cavities by providing limited funding for children up to age 18. Eligible families are typically uninsured or underinsured and are otherwise unable to obtain dental treatment. Treatment funding is provided at reduced rates. Call Rady Children's Healthcare Referral at (800) 788-9029 to apply.

**SDG&E:** Your family may qualify for a discounted energy bill based on your income. See your discharge planner for an application.

## Additional Family Resources

**San Diego Regional Center:** A state-funded program for diagnosing and serving individuals who have developmental disabilities or young children at high risk for developmental disabilities. The Regional Center will provides multiple services including diagnosis, treatment programs, transportation and respite services. For more information, call (858) 576-2996.

**Exceptional Family Resource Center (EFRC):** EFRC provides families with emotional support, factual information and encouragement in order to help children reach their full potential. Agency services include education and lending library, local, regional and national resources, referral to community-based programs, support groups and disability-specific support groups. For information call (800) 281-8252.

**Outreach and Early Intervention Program:** This is a family-focused program that provides services to promote optimal development and minimize developmental delays in infancy. One of the services offered is respite care. Ask your discharge planner about a referral for this service.

**San Diego Network of Care:** A comprehensive resource for services provided in San Diego County. You can access their website at <http://sandiego.networkofcare.org>.

**HowKidsDevelop.com:** A collaborative website with information on the Developmental Screening and Enhancement Program (DSEP), Children's Care Connection (C3), First Five Healthy Development Services Initiative (HDSI) and Rady Children's Hospital Developmental Services.

## Medical Glossary

**Balloon port:** Allows the balloon to be inflated and deflated.

**Bolster:** A round plastic disk resting on the skin of your child's tummy which holds the g-tube securely in place.

**Bumper:** A small rubber disk that lies inside your child's stomach holding the PEG Tube in place.

**Clamp:** Keeps the tube closed when not in use preventing leakage of milk.

**Decompressing the Stomach:** Emptying the stomach of air and feedings.

**Esophagus:** Tube that carries food from the mouth to the stomach.

**Feeding port:** Where the feeding tube or extension tube will attach to give liquid feeds.

**Fundus:** The upper part of the stomach.

**Fundoplication:** A surgical operation that takes the upper portion of the stomach and wraps around esophagus.

**Gastric port:** Where feeding tube attaches to a g-tube for feeding or medications.

**Gastric Secretions or Gastric:** Stomach secretions and contents.

**Gastro-Esophageal Reflux Disease (GERD):** gastric secretions going from the stomach into the esophagus.

**Gastrostomy:** A surgical opening (hole) into the stomach.

**Gastrostomy Tube (G-Tube):** A tube that is placed into the gastrostomy hole.

**Gastro-Jejunal Tube (G-J Tube):** A tube that is placed into the gastrostomy hole, into the stomach and then out to the jejunum below. This tube provides access to both the stomach and the jejunum via separated ports.

**Jejunum:** A tube that lies below the stomach and carries food away.

**Jejunal port:** Where main feeding tube attaches to a G-J tube for jejunal feeding.

**Medicine port:** A port for giving liquid medications.

**Mic-key bolus extension tube:** Tube is used for venting, checking tube placement and bolus feeding.

**Mic-key extension tube:** This extension tube can be used for venting, checking tube placement and feeding.

**Red Robin Tube:** A temporary tube that is placed in a gastrostomy hole when the g-tube falls out.

**Secur-Lok connector:** This end of the extension tube fits directly into the gastric (stomach) and Jejunal ports of the mic-key button tubes.

**Silicon balloon:** Holds the tube in place when it is inflated with sterile water.

**Stoma:** A small hole through the abdomen where your child's g-tube is inserted.

**Venting:** Burping your child through the g-tube.

## Common Questions

<p><b><u>Why does my child need a PEG tube?</u></b></p>	<p>Your child may be unable to tolerate taking enough feeds by mouth at this time to allow them to grow and gain weight. The g-tube will allow them to get all the calories and nutrition they need to grow and develop.</p>
<p><b><u>How long will my child have the PEG tube?</u></b></p>	<p>The length of time your child will have the PEG tube depends on their specific needs. Your child's future plans can be discussed with your child's GI Physician.</p>
<p><b><u>What will my child look like after surgery?</u></b></p>	<p>Your child may come back from the procedure awake but sleepy. Depending on the GI Physician your child will have a g-tube in place and in most cases no visible wounds. Any incisions will have a dressing over them.</p>
<p><b><u>When can I hold my child?</u></b></p>	<p>Your child will be sore after the procedure and we will make sure that he/she get adequate pain medication. It is sometimes best to let him/her rest and heal in bed for the first few hours/days after surgery. Discuss with your child's nurse when you will be able to hold him/her.</p>
<p><b><u>When will my child start getting breastmilk/formula through the PEG tube?</u></b></p>	<p>Once your child has recovered from the procedure your doctor will decide when to start feeds. Usually we start with a clear liquid called pedialyte and then progress to breastmilk or formula. We normally start with small amounts of milk given continually and increase as your</p>



## Common Questions

Continued

<p><b><u>Is it safe for my child to eat food or milk by mouth?</u></b></p>	<p>Your child's Doctor and Occupational Therapist will discuss when it is possible for your child to eat food by mouth. Your Occupational Therapist will show you some exercises to encourage your child's development and prepare them for taking foods by mouth.</p>
<p><b><u>Can I give my child a bath when they have a PEG tube?</u></b></p>	<p>Your child can have a tub bath once the incisions and site have healed. This is normally around 14 days after surgery. Discuss with your child's GI Physician when it is safe for your child to start having tub baths.</p>

## Problem Solving

<p><b><u>Child has difficulty breathing.</u></b></p>	<p>If your child develops difficulty breathing during or immediately after a feeding, <b>STOP THE FEEDING AT ONCE</b>. Empty the stomach immediately (pg. 25). If breathing problems continue, <b>call 911</b></p>
<p><b><u>Child is vomiting</u></b></p>	<p>This can be caused if the feeding has gone in too fast, if the formula is too cold, too hot or spoiled. It can also happen if a new medication or formula is being given. Vomiting can also be a sign of infection.</p> <ol style="list-style-type: none"> <li>1. Try giving feed at a slower rate.</li> <li>2. Try warming formula up to room temperature.</li> <li>3. Only keep formula for 24 hours once you have mixed it.</li> <li>4. Keep formula in fridge once it has been mixed.</li> <li>5. Always wash your hands before preparing milk formula.</li> <li>6. Call your doctor if vomiting continues or your child has any other signs of illness.</li> </ol>
<p><b><u>Child has diarrhea</u></b></p>	<p>This can be caused if the feeding has gone in too fast, from spoiled formula or breast milk. It can also happen if a new medication or formula is being given. Diarrhea can also be a sign of infection.</p> <ol style="list-style-type: none"> <li>1. Try giving feed at a slower rate.</li> <li>2. Only keep formula for 24 hours once you have mixed it.</li> <li>3. Keep formula in fridge once it has been mixed.</li> <li>4. Always wash your hands before preparing milk formula.</li> <li>5. Call your doctor if diarrhea continues or your child has any other signs of illness.</li> </ol>
<p><b><u>Child has constipation</u></b></p>	<p>Constipation can be caused by a change in formula or medication. It can also be caused by a change in feeding schedule. Let your doctor know if constipation continues.</p>

Problem Solving  
Continued

<p><b><u>Tube blocked</u></b></p>	<p>This can be caused by thick formulas or medications.</p> <ol style="list-style-type: none"> <li>1. Try gently flushing with warm water.</li> <li>2. Call your doctor if you are unable to unblock the tube.</li> </ol>
<p><b><u>PEG tube falls out</u></b></p>	<p>Cover, stoma with gauze and get your travel kit.</p> <ol style="list-style-type: none"> <li>1. <u>Less than 6 weeks</u> after placement, cover stoma with gauze and then go to Emergency Dept.</li> <li>2. <u>More than 6 weeks</u> after placement and you have been trained, place red robin tube and then call GI Physician and go to Emergency Dept.</li> <li>3. <u>More than 6 weeks</u> after placement and you have been trained, place g-tube and then call GI Physician for follow up care.</li> </ol>
<p><b><u>Extension tubing Leaking</u></b></p>	<p>Sometimes the medication port of the extension tube starts to become loose and pops off, letting milk leak out.</p> <ol style="list-style-type: none"> <li>1. Always make sure you push the plug into the medicine port after giving medications and before starting feeds.</li> <li>2. If it continues to leak, change out the extension tube.</li> </ol>
<p><b><u>Leaking around the PEG tube site</u></b></p>	<p>Leakage can occasionally occur around the tube site and can be caused by feeds being given too fast, too much feed being given, reduced inflation of the balloon and the need for a new larger sized tube.</p> <ol style="list-style-type: none"> <li>1. Try giving feed at a slower rate.</li> <li>2. Check the amount of water in the balloon and top up if needed.</li> <li>3. If your child has suddenly gone through a growth spurt, check with your doctor to see if he/she requires a larger g-tube.</li> <li>4. Keep the tube out of your child's reach to stop him/her playing and pulling on it. Secure it under his/her clothes.</li> </ol>

## Recommended Reading

### Caregiver Support:

[www.KCDigestiveHealth.com](http://www.KCDigestiveHealth.com)

[www.tubiefriends.com](http://www.tubiefriends.com)

[www.oley.org](http://www.oley.org)

[www.mic-key.com/facebook](http://www.mic-key.com/facebook)

[www.mic-key.com/blog](http://www.mic-key.com/blog)

[www.mealtimenotions.org](http://www.mealtimenotions.org)

[www.emdn-mitonet.co.uk/PDF/bookGTube.pdf](http://www.emdn-mitonet.co.uk/PDF/bookGTube.pdf) (*Helpful book for older children!*)

### Acknowledgements:

Photographs ... Linda Black RNC - NIC, CLE, RNM

Concept, Design and Layout ... Linda Black RNC - NIC, CLE, RNM

Collaborative Team .. Rady Children's Hospital Tips and Tubes Committee 2014

### References:

Reckling, A, PsyD. (2007) *When Jeremy Jones' Stomach Stopped Working*. Mitochondrial Disease Action Committee.  
<http://www.mitoaction.org/pdf/bookGTube.pdf>

*Mic-Key Tube Care and Usage* (2010). Kimberly-Clark Worldwide, Inc.  
<http://www.mic-key.com/resources/mic-keystar-care--usage-guide.aspx>

Su W, Berry M, Puligandla PS, Aspirot A, Flageole H, Laberge JM. *Predictors of gastroesophageal reflux in neonates with congenital diaphragmatic hernia* (2007).  
<http://www.ncbi.nlm.nih.gov/pubmed/17923189>

*History of the Nissen Fundoplication* (2011). TEF/Vater Internatioanl.  
<http://www.tefvater.org/esophageal/funduplications.html>

Cu S, BS; Sidman J, MD. *Rates and Risks of Gastrostomy Tubes in Infants With Cleft Palate* (2011).  
<http://archotol.ama-assn.org/cgi/content/abstract/137/3/275>

*Fundoplication - Open Surgery* (2005). EBSCO Publishing.  
<http://www.doctorsofusc.com/condition/document/14813>

Minard G, MD. *The History of Surgically Placed Feeding Tubes* (2006).  
<http://ncp.sagepub.com/content/21/6/626.abstract>

*Gastrostomy Tubes* (2011). The Regents of the University of California.  
<http://pedsurg.ucsf.edu/conditions--procedures/gastrostomy-tubes.aspx>

Agrawal S. *All About NJ, GJ, and J Tubes* (2009). Complex Child E-Magazine.  
<http://www.articles.complexchild.com/oct2009/00158.pdf>

Sexton E, Holden C. *Jejunostomy Tubes* (2007). Tracheo-Oesophageal Fistula Support.  
[http://www.tofs.org.uk/index.php/what\\_is\\_tof\\_oa/procedures/jejunostomy\\_tubes](http://www.tofs.org.uk/index.php/what_is_tof_oa/procedures/jejunostomy_tubes)

*Enteral Feeding: Enteral Feeding Tubes & Accessories* (2009). Kimberly-Clark Worldwide, Inc.  
<http://kchealthcare.or-live.com/digestivehealth/enteralfeeding/product/acc.cfm>

World Ostomy and Continence Nurses Society  
<http://www.wocn.org>



## My Journal

A large, light blue rectangular area with rounded corners, containing 20 horizontal blue lines for writing.



3020 Children's Way  
San Diego, CA 92123  
(858) 966 1700  
[www.RCHSD.org](http://www.RCHSD.org)

