

Tube Feeding at Home

**A Guide for
Families
and
Caregivers**



**CHILDREN'S & WOMEN'S HEALTH
CENTRE OF BRITISH COLUMBIA**

An agency of the Provincial Health Services Authority (PHSA)

May 2003

Fourth Edition, 2003

The practices of nutrition support are continually evolving with new knowledge and guidelines from expert authorities. This booklet is being published with the aim of providing guidelines for tube feeding that are consistent with the most recent scientific data. Where research is not available, the practice guidelines are the best as derived from the collective experience of the health professionals at Children's and Women's Health Centre.

The development of these guidelines involved thorough and repeated review by health professionals at Children's and Women's Health Centre in the fields of neonatology, pediatrics, nursing, infectious disease, nutrition and public health. The input of these professions has been invaluable and we are most grateful for their assistance.

The publisher is not responsible (as a matter of product liability, negligence, or otherwise) for any injury resulting from any material contained herein. This booklet contains information relating to general principles of medical care and should not be construed as specific instructions for individual patients. Product information and package inserts provided by the manufacturer should be reviewed for current information including contraindications, dosages and precautions.

This booklet was developed and printed with the support of the Sunny Hill Hospital Auxiliary.

All parts of this publication may be reproduced, stored in a retrieval system or transmitted in any forum by any means – electronic, mechanical, photocopying, recording or otherwise – without requesting the prior permission of the Nutrition Committee, Children's and Women's Health Centre.

To purchase additional copies of this booklet call 1-888-727-7759, the Special Products Distribution Centre located at Children's and Women's Health Centre.

Dr. Sheila Innis, Chair
Nutrition Committee
Children's and Women's Health Centre of BC

Table of Contents

Introduction: What is Tube Feeding?	1
The Digestive System.....	2
Gastrostomy and Jejunostomy Tubes	3
Information about your child's feeding tube	4
Gastrostomy Tubes: G-Tubes.....	5
Low Profile Gastrostomy Devices.....	6
Jejunostomy Tubes: J-Tubes	8
Caring for the Stoma and Feeding Tube.....	10
Checking the Stoma and Feeding Tube.....	12
Cleaning the Stoma and Feeding Tube.....	13
Caring For The Mouth.....	14
Oral Stimulation During Tube Feeding	15
Transition From Tube To Oral Feeds	16
Tube Feeding Schedules: Intermittent and Continuous.....	17
Tube Feeding Formula	18
Information about your child's tube feeding supplies	19
Tube Feeding Schedule: <i>Intermittent (Bolus) Feeding</i>	20
Tube Feeding Schedule: <i>Continuous or Overnight Feedings</i>	22
Giving Tube Feedings	23
Giving Medications through a Feeding Tube	29

Preventing and Solving Problems (Alphabetical Order)	32
Telephone Numbers	48
Appendix A: Monitoring Progress	50
Appendix B: Ongoing Questions & Concerns	52
Appendix C: List of Terms.....	53
Appendix D: Additional Resources for Families & Caregivers	55
Appendix E: Reinserting a Gastrostomy Tube (G-Tube).....	56
Appendix F: Reinserting a Jejunostomy Tube (J-Tube).....	58
References.....	59

Figures Table of Contents

<u>Figure</u>	<u>Title</u>	<u>Page</u>
1	The Digestive System	2
2	Placement of Feeding Tube.....	3
3	PEG –Tube with Port	5
4	Placement of Feeding Tube	5
5	Bard Button.....	6
6	MIC-Key Skin Level Device	7
7	J Tube.....	8
8	Radiologically-Placed Tube	9
9	G-J-Tube	9
10	Foley Gastrostomy Tube	56

Introduction: What is Tube Feeding?

Tube feeding is a way of giving liquid food (often formula) directly into the stomach or small bowel. This formula provides the body with the nutrients needed for good health. Tube feeding can be used for children who:



- Cannot eat at all
- Do not feel hungry
- Need extra nutrition – higher amounts of protein and calories
- Cannot eat or drink enough regular food or fluids because they tire easily or cannot chew or swallow well.

Right now, you might feel quite overwhelmed by the idea of tube feeding at home. Please know that we will teach you what you need to know before you go home with your child. You will also be able to practice your new skills before going home. Please ask any questions or discuss any of your concerns with us. There is no such thing as a silly question!

**Please discuss
any questions
or concerns
with us.**

The information in this booklet will help you to carry out tube feeding at home. Please feel free to write notes or questions in it. It might also be helpful if you bring this booklet to your appointments.



The Digestive System

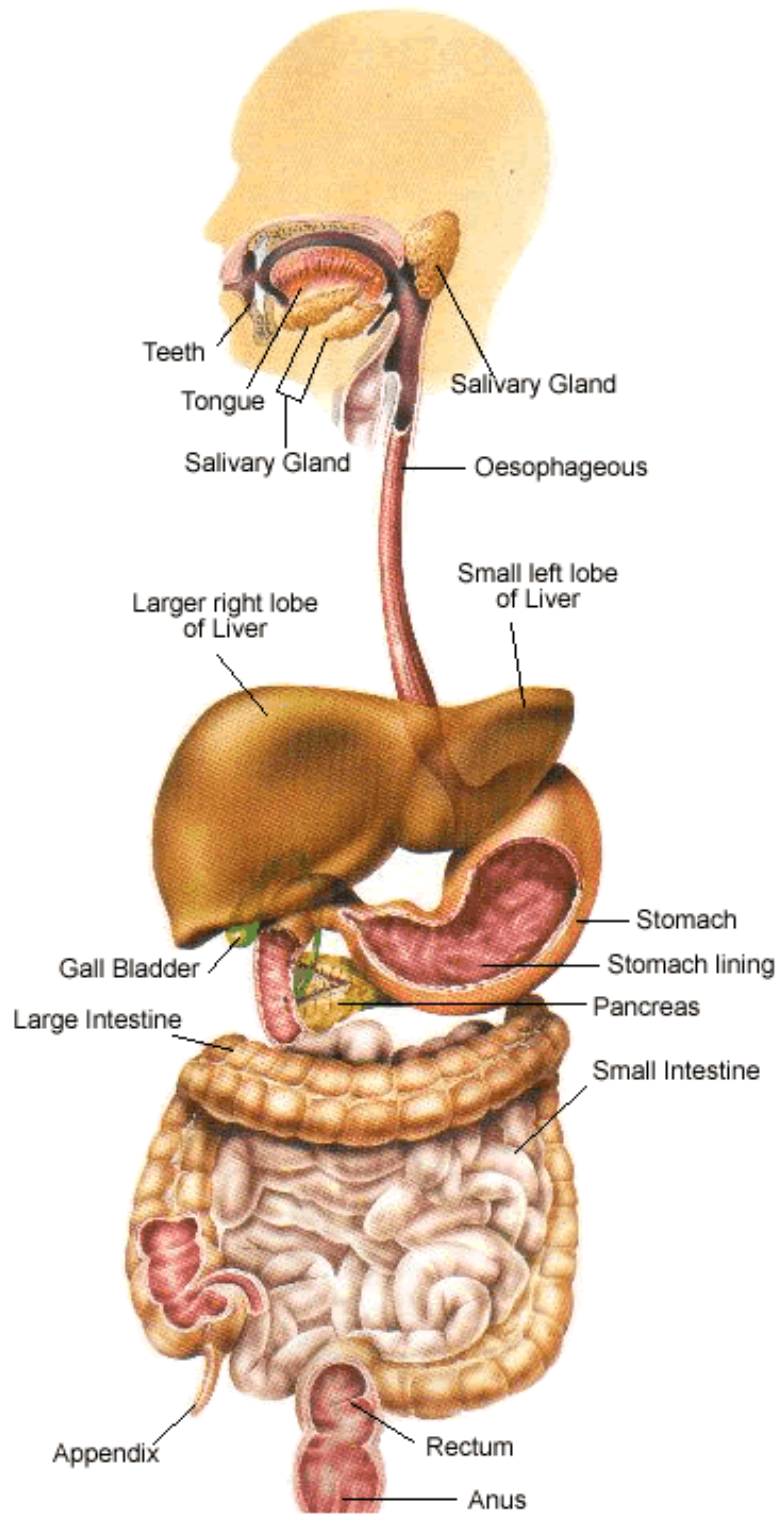


Figure 1: The Digestive System

Gastrostomy and Jejunostomy Tubes

There are many different types of tubes used. The tube chosen depends on the needs of the child. All of the tubes are soft with rounded tips on the end that is inside the body. There are one or more openings, called “ports”, on the other end of the tube that is outside of the body. These openings or “ports” are used to connect the feeding bag.

A **gastrostomy (G-tube)** or **jejunostomy tube (J-tube)** is a small soft tube that goes into the body through an opening in the abdomen and ends inside the stomach (G-tube) or small bowel (J-tube). The liquid food (formula) goes through this tube into the stomach or small bowel.

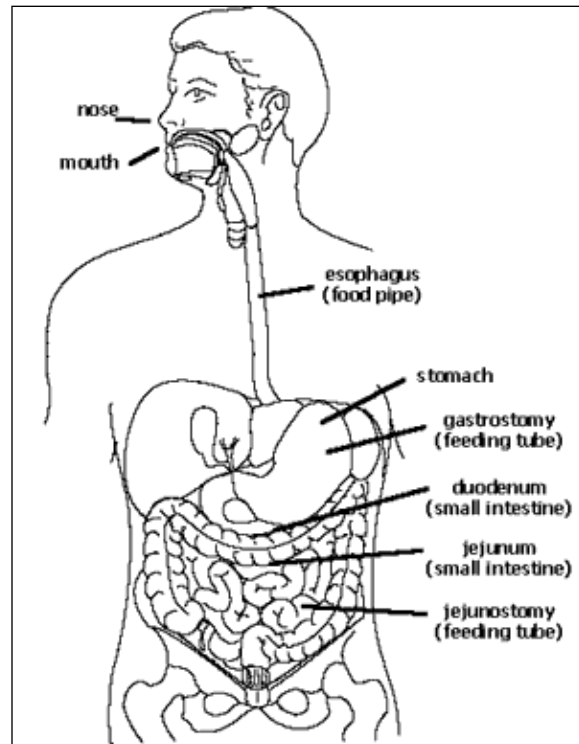


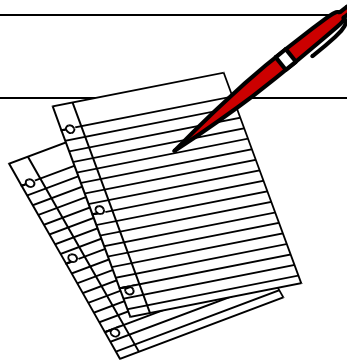
Figure 2: Placement of Feeding Tube

Information about your child's feeding tube

**Write your
child's
information
here.**

**Keep this page for
your records.**

1. Tube type and brand:
2. Tube size:
3. Health Care Provider that inserted the tube:
4. Date the tube was inserted:
5. Date when tube should be changed:
6. Where to go to have the tube changed and who can change it:
7. Other details:



Gastrostomy Tubes: G-Tubes

G-tubes are placed into the stomach and come out through the skin of the abdomen. They may be held in place by sutures, an inflated balloon, by internal/external bumpers or by a disc.



Figure 3: PEG with Port

**Different types
of tubes.**

**The tube chosen
depends on your
child's needs.**

Here are some examples of different types of G-Tubes:

■ PEG Tube (Percutaneous Endoscopic Gastrostomy)

This is a silicone tube inserted by a surgeon or gastroenterologist in a hospital. It is inserted under general anesthesia or sedation. A surgeon or gastroenterologist will change the tube as needed.

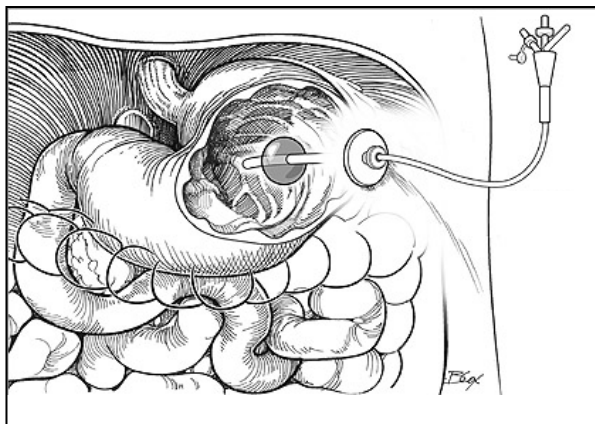


Figure 4: Placement of Feeding Tube

■ Gastrostomy Balloon Type Tubes

Initially, a surgeon or gastroenterologist puts in these tubes. Gastrostomy tubes last from 6 weeks to 6 months depending on the tube. A nurse or skilled caregiver in the home or hospital can change them.

Low Profile Gastrostomy Devices

These are small, flexible silicone rubber devices that can be put in surgically or can be used to replace the original gastrostomy tube (described above). They are called “low profile” because they are small and at skin level. They can be held in place by an internal bumper or balloon.

Here are some examples of different types of gastrostomy devices:

■ **Bard Button**

A Bard Button is most often inserted into an established stoma. It can last for about 12 months.



Figure 5: Bard Button

Gastrostomy devices continued...

■ **MIC-KEY**

Is inserted surgically or inserted into an established stoma and lasts about 4 – 6 months. These tubes can be changed at home.

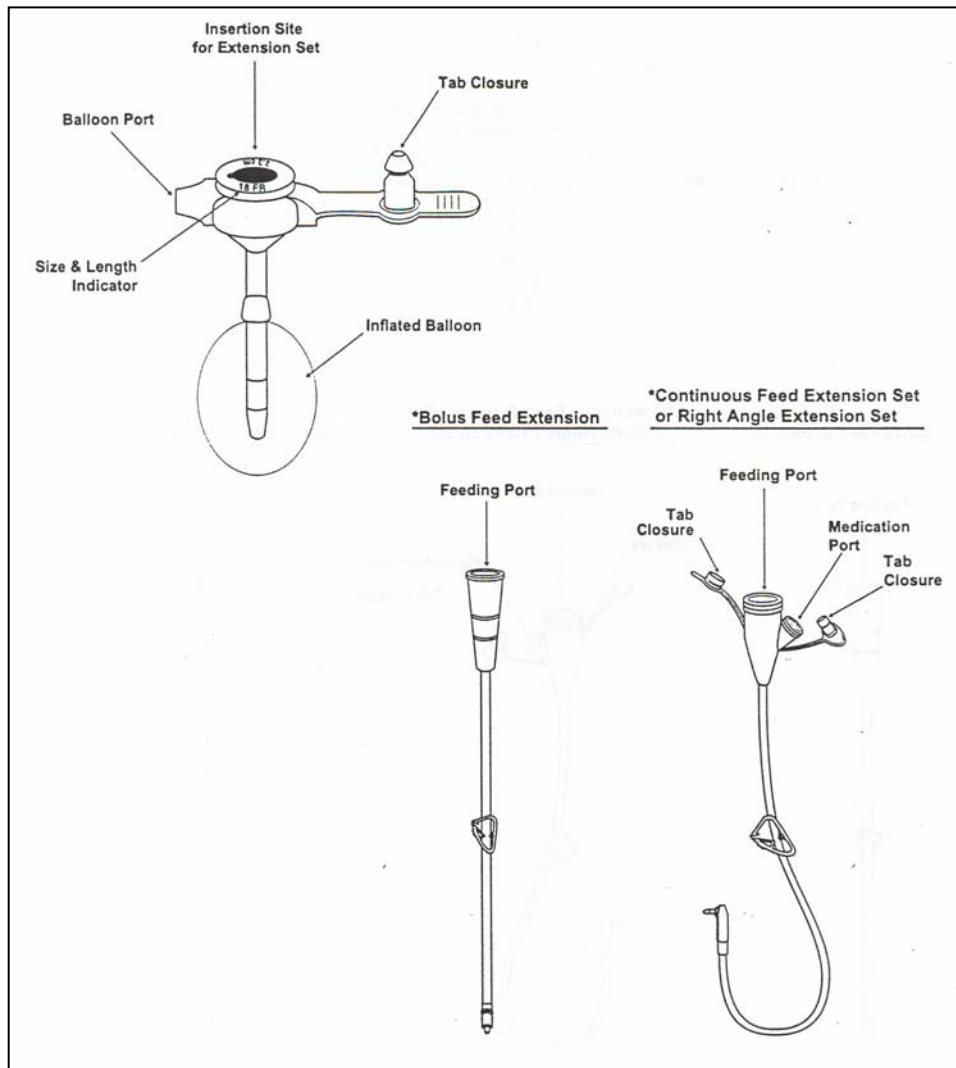


Figure 6: Mic-Key

Jejunostomy Tubes: J-Tubes

Here are some examples of different types of J-Tubes:

- **Surgical Jejunostomy Tube (J-Tube)**

A surgical jejunostomy is a tube that is placed into part of the small bowel (jejunum) by a surgeon. This tube will last about 1 – 2 years.

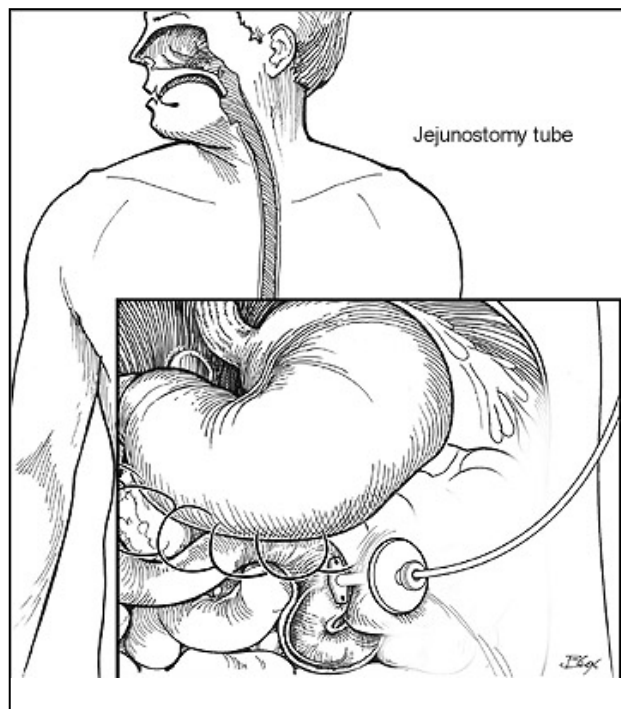


Figure 7: J-Tube

- **Radiologically-Placed Jejunostomy Tube through an established Stoma**

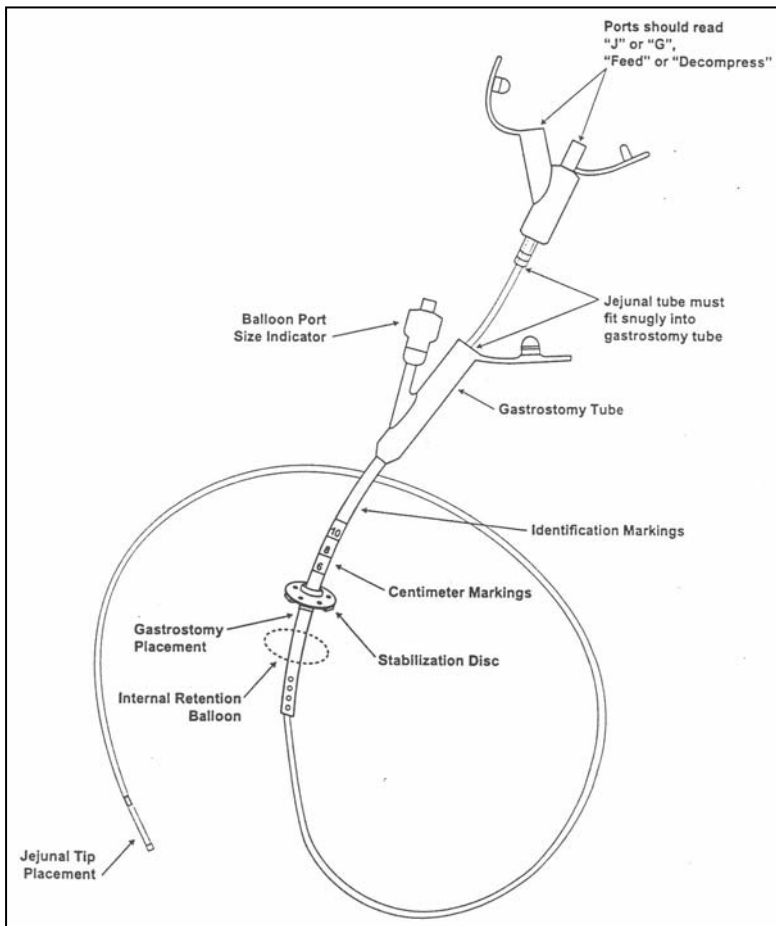
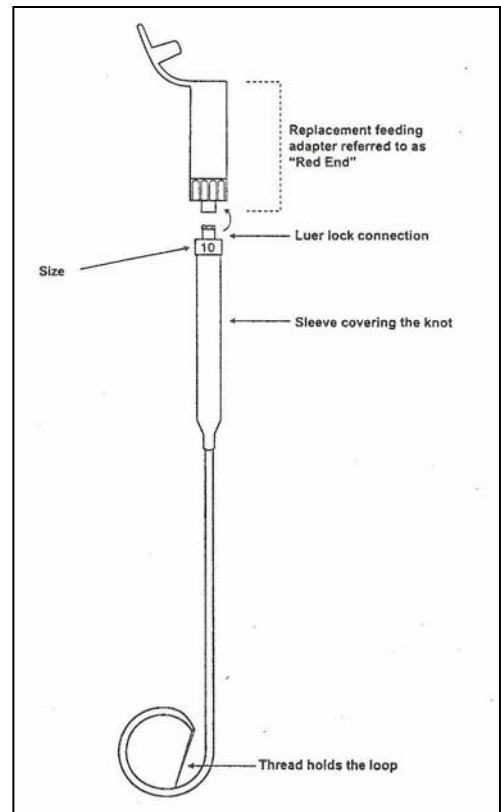
Under local anesthetic, this tube is inserted by a radiologist in the hospital. It is changed every 3 – 6 months.

J - tubes continued...

■ **Radiologically-Placed Gastrostomy - Jejunostomy (G-J) Tubes**

A radiologist in a hospital inserts these tubes. They are inserted under anesthesia. These tubes are usually changed every 3 – 6 months by a radiologist.

Figure 8: Radiologically Placed Tube



COMBINED TUBE:

■ **Gastrostomy-Jejunostomy Tube (G-J Tube)**
A G-J tube is a tube that is put through the stomach via the gastrostomy into the jejunum. It is inserted by a radiologist and is replaced every 3 - 6 months.

Figure 9: G-J Tube

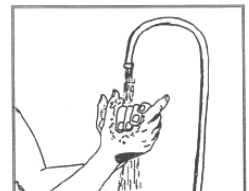
Caring for the Stoma and Feeding Tube

GENERAL INFORMATION:

- The stoma is a surgically created opening on the skin where the feeding tube enters the body.
- **Always** keep the skin around the stoma and under the bumper/disc/button as clean and dry as you can. The skin disc or bumper on the outside of the tube should be approximately ½ inch (about the width of a dime) away from the skin.
- Do **not** apply creams or dressings to the stoma unless your nurse or primary health care doctor has suggested this. Most skin irritations heal quickly when left open to the air. Creams and dressings stop the air from reaching the stoma.
- **Always** make sure that the feeding tube is in the correct position before starting a tube feeding or giving medication. To check the position of a gastrostomy tube, gently pull back on the tube to make sure it is against the stomach wall and then measure the length of the feeding tube that is outside of the body (see *page 4* for the length that it should be).
- Wait **at least 7 days** after new the tube is inserted before swimming or bathing. When you go swimming, tape the tube securely to your child's stomach using a waterproof tape.
- Participation in sport activities is fine once the stoma is no longer tender. If there is a hit to the abdomen, there may be some pain but it is usually not an emergency unless the pain is intense or the pain does not get better. It is best to have the tube checked by a primary health care doctor or nurse if the pain is intense or does not get better or if there is any bleeding or bruising around the child's stoma site.
- Children can lie in any position that is comfortable. It is best to try and prevent babies and other children from pulling or playing with the tube. You can cover the tube with an undershirt or sleeper. Try to keep the stoma and tubing outside of the diaper to keep it clean.
- Before you care for the stoma or tube - **wash your hands!** Washing your hands can prevent the spread of illness! Washing your hands is one of the most important steps you can take when caring for your child's tube feed.

The BASICS.

**Remember
washing your
hands is one of the
most important
steps you can take
when caring for
your child's tube
feed.**



- **When washing your hands please make sure you:**

- Remove rings and watch. These can trap germs.
- Use warm water and regular soap and rub all parts of your hands and wrists. Friction is the best way to get rid of harmful germs.



- **Wash for 30 seconds. Hint:** Sing “*Happy Birthday to You*” (the whole song) and 30 seconds will have passed.



- Rinse well. Leave the taps running and dry your hands with a clean towel.
- Turn off the taps with the towel.

Checking the Stoma and Feeding Tube



GENERAL INFORMATION:

With every feed, check the following things:

A.

The Skin – Problems to watch for:

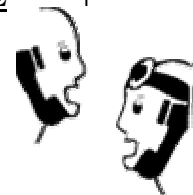
- Skin redness greater than 1/2 inch (1 to 2 centimeters) around the tube
- Tenderness, discomfort or pain around the tube
- Discharge (leakage) from the stoma.
- Swollen skin
- Bad smell

➔ If you see any of these, go to *pages 43 & 44* to find out what to do.

B.

The Tube:

- Check the feeding tube for any leaks or cracks.
➔ If it is cracked or leaking, go to *pages 40 & 41* to find out what to do.
- Measure the length (position) from the stoma to the end of the tube. Write this number down. Compare the measurement to the measurement you made when the tube was first inserted.
➔ If it is shorter than it should be, the tube may have moved into the stomach (*see page 4*) Gently pull on the tube until the internal bumper balloon is snug against the stomach wall. Then measure again to make sure it is the right length.
➔ If it is longer in length, the tube may be coming out. **DO NOT USE** the feeding tube. Call the nurse or primary health care doctor.



Cleaning the Stoma and Feeding Tube

GENERAL INFORMATION:

Keeping the skin clean and dry helps avoid skin irritation and breakdown. Usually you will clean the stoma and tube twice (**2 times**) each day. Using a clean wash cloth or cotton ball, wash the skin around the tube with mild soap and water. Also clean the skin anytime there is leakage around the tube.

HOW TO CLEAN THE STOMA AND FEEDING TUBE

(The nurse will check which steps should be followed):

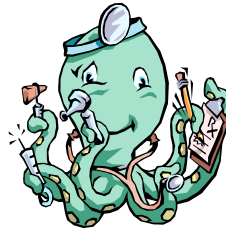
Step 1 Prepare and clean work area, and wash your hands! Washing your hands can prevent the spread of illness! Washing your hands is one of the most important steps you can take when caring for your child's tube feed.



Step 2 Gather the equipment:

- Clean wash cloth
- Cotton balls
- Cotton tip swab (Q-tip)
- Mild Soap
- Warm water

- Other: _____



Step 3 Wash your hands again before touching the equipment and patient/child. Gently lift the sides of the disc or tube to reach all areas of the skin. Do not pull hard on the tube. This can hurt the inside of the stomach or intestine.

Step 4 Use a cotton swab or Q-tip to gently clean under the disc or around the tube.

Step 5 Clean the outside of the tube with soap and water.

Step 6 Rinse the skin with warm water. Pat the skin well with a soft towel or leave open to air.

Step 7 Seven days after having a gastrostomy tube surgically inserted, your child can soak in a bath tub or go into a swimming pool. The tube and stoma can be easily cleaned in the bath tub.

Step 8 If you use tape to keep the tube in place, do not tape over the same patch of skin each time as this can irritate the skin. When you tape the tube, loop the tube loosely and tape it to the skin.

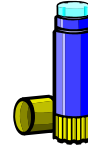
Step 9 Wash your hands once again after you are all finished.

Caring For The Mouth

- Brush your child's teeth at least twice a day. If the child is able, he or she can do it.



- Rinse your child's mouth with water, mouthwash, toothette or cloth frequently



- Put a lip moisturizer on the lips to keep them moist.

- To help make saliva flow and keep the mouth clean and moist, a toothette¹, Gum Stimulator set, hand or a soother may be used.

¹ Toothettes should not be used with children who have a strong bite reflex.

Oral Stimulation During Tube Feeding

For children who cannot eat or drink by mouth, tube feeding does not mean the end of pleasures associated with eating. Some children are able to take small amounts of food.

It is easier to increase oral feeding than to completely restart it. Oral-motor stimulation can be nutritive (with tastes) or non-nutritive. Your doctor can tell you which is best for your child. Including an oral-motor stimulation program at daily mealtimes will help create a positive approach.

Extended periods of tube feeding can contribute to reduced oral-motor skills.

Unpleasant procedures and experiences may result in oral aversion (hypersensitivity and defensiveness around the face and mouth).



General Principles Of Oral-Motor Stimulation

1. It should be fun and enjoyable for child and caregiver.
2. Incorporate into regular play times and during tube feeds.
3. If child does not tolerate or becomes stressed, stop and try again later at a level of stimulation that s/he likes and slowly work at progressing stimulation.

PLEASE USE THE FOLLOWING AS A GUIDE TO HELP YOUR CHILD:

Non-nutritive Oral-Motor Stimulation

1. Pleasant touch around mouth area i.e. Cotton balls, terry cloth, soft toothbrush, soft toys.
2. Explore shapes and textures such as teething toys, own hands, nipples and spoon, especially shapes that your child will eventually use to feed with.
3. Massage should be firm but gentle on the upper body and face.
4. During tube feeding times, encourage your infant to suck on a pre-pumped breast or soother.

Nutritive Oral-Motor Stimulation

1. Offer tastes of a variety of suitable foods/liquids. Some children enjoy strong flavors.
2. Dip soother, infant spoon or teething ring into milk or purees for child to taste.
3. Rub lips and gums with small amounts of food/liquid then place some centrally on tongue to encourage sucking or tasting.

Sensory stimulation is also an important part of a tube feeding.

Transition From Tube To Oral Feeds

GENERAL INFORMATION:

- It is very important that the child who is going to be moving from only having tube feedings to oral feeds learn how to eat safely. The transition from feeding a child through a tube to oral feeding is a process that usually requires planning and support.
- First, an experienced occupational therapist and/or speech-language pathologist should assess a child's eating and swallowing skills.
- Once a child is starting to eat, a nurse and/or dietitian will provide support to ensure that the process is going smoothly.
- This is a very individual process and needs careful assessment and planning. If an occupational therapist or speech-language pathologist does not follow your child, request a referral from the primary health care doctor before starting to feed your child by mouth.

This is a very individual process and needs careful assessment and planning.

READINESS FACTORS TO CONSIDER PRIOR TO MAKING THE TRANSITION FROM TUBE TO ORAL FEEDING:

1. The medical conditions(s) that resulted in tube feeding should be resolved or stabilized.
2. Can your child eat safely and in a reasonable length of time?
Indications of an unsafe swallow may include:
 - Inability to handle saliva/secretions
 - Noisy, wet sounding breathing
 - Multiple swallows to clear food
 - Frequent unexplained respiratory illnesses
 - Coughing/choking while eating or drinking
 - Changes in their breathing while eating or drinking
Eg. Stops breathing, oxygen saturation changes, color changes
3. Nutritional readiness
 - Can your child tolerate intermittent feeds?
 - Is there sufficient weight gain to tolerate a possible small loss while transitioning?
4. Behavioral readiness
 - Is your child showing hunger cues?
 - Is your child showing an interest in food?
5. Social factors
 - Caregiver would need motivation, skills, time and support for successful transition from tube to oral feeding

Tube Feeding Schedules: Intermittent and Continuous

There are different types of feeding schedules used. Your schedule will depend on the child's nutritional needs as well as life style.

Different types of feeding schedules.

The feeding schedule chosen depends on your child's nutritional needs as well as lifestyle.

When the feeding tube is first put in, it is common for tube feedings to begin as a slower continuous feed to help the body get used to the formula then move to an intermittent feeding schedule.

Intermittent Feedings



Intermittent feedings, sometimes called bolus feedings, are tube feedings given over short periods of time several times throughout the day. These feedings can be given by a pump or by gravity.

The timing of the tube feedings can be changed to allow 2 – 3 hours between the end of one feed and the start of the next feed to allow time for the stomach to empty. Intermittent feedings resemble the normal pattern of eating and digestion.

Continuous Tube Feedings

Continuous feedings are given at a steady rate, for as many hours as needed, over a 24-hour period to provide the energy and nutrition required. A pump will be used to control the steady rate of these tube feedings.



A feeding into the jejunum tube is usually given at a slow continuous rate because, unlike the stomach, the small bowel is not able to hold large amounts of formula. In certain situations a feeding into the stomach may also be given as a continuous feed.

Combined Intermittent (bolus) and Continuous Tube Feedings

In some situations bolus tube feeds are given during the day and continuous tube feeds at night.

Tube Feeding Formula

There are more than 80 types of formula products available. The dietitian will discuss with you the best type of formula for your child.

The dietitian will discuss with you what the best type of formula for your child is.

Infants (0 - 12 months)

An infant under a year of age will usually receive expressed breast milk and/or infant formula for the tube feeding.



Children (1 – 10 years old)

A child will usually receive a pediatric formula that is made to meet the specific nutrient needs of this age group.



Older children (over 10 years of age) and adults



Both the older child and adult will usually receive a formula that is made to meet the specific needs of this age group.

Depending on the situation, the dietitian may recommend adding vitamins and/or minerals to the formula as needed.

Information about your child's tube feeding supplies

**Write your
child's
information
here.**

**Keep this page for
your records.**

1.	Tube feeding formula:
2.	Alternate formula:
3.	The brand, type and size of feeding bag and tubing to use:
4.	Type of adaptor
5.	Syringes
6.	Replacement feeding tube:
7.	Foley Catheter Size # _____ (in case tube falls out)
8.	If used, the brand of the pump:
9.	The formula and feeding bags can be obtained from: <input type="checkbox"/> At Home Program <input type="checkbox"/> Medical Supply Companies such as: _____ <input type="checkbox"/> Home Enteral Nutrition Program
10.	Other details:

Supplies can be purchased from:

The Special Products Distribution Centre
Room A109
Children's & Women's Health Center of BC
4500 Oak Street
Vancouver, B.C. V6H 3N1
Telephone: 604-875-3020
Toll Free: 1-866-727-7759



**Write your
child's
information
here.**

**Keep this page for
your records.**

Tube Feeding Schedule: *Intermittent (Bolus) Feeding*

Date:		Name:	
1. Formula:		Size:	(i.e. ml) = containers/cans
Formula:		Size:	(i.e. ml) = containers/cans
Formula provides:	Kcalories	grams of protein/day	ml of free fluid/day
2. Number of tube feedings each day:			
3. Amount of formula at each feeding: <i>(see Feeding Schedule next page)</i>			
4. Amount of water flush before each feeding: <i>(use syringe to flush tube)</i>			
5. Amount of water flush after each feeding: <i>(use syringe to flush tube)</i>			
6. Give each feeding over: minutes/hours or at the rate of:			
7. Goal for weight:		pounds	kilograms
8. Weigh and record your child's weight every: days <i>(see Appendix A: page 50)</i>			
9. Other pertinent information:			



Phone the healthcare provider if you have any questions about this schedule. This includes questions about the amount of formula, feeding times, and weight gain, etc.

Contact Name: _____

Phone : _____

Tube Feed Schedule

Time of Day							
Formula & Amount							
Water added to feeding bag							
Water flush before and after feeding							
Medications							
Water before and after medications							

Write your child's information here.
Keep this page for your records.

Tube Feeding Schedule: *Continuous or Overnight Feedings*

Date:	Name:
1. Formula:	Size: <i>(i.e. ml)</i> = containers/cans
Formula:	Size: <i>(i.e. ml)</i> = containers/cans
Formula provides: Kcalories grams of protein/day ml of free fluid/day	
2. Start time(s) of tube feeding:	
3. End time(s) of tube feeding:	
4. Give each feeding over: minutes/hours or at the rate of:	
5. Flush feeding tube with: ml of water every: hours <i>(use syringe to flush tube)</i>	
6. Wash and rinse the tube feeding bag every four (4) hours throughout the day and night or use an alternate set of bag and tubing. See <i>page 27</i> for complete instructions.	
7. Goal for weight: pounds kilograms	
8. Weigh and record your child's weight every: days <i>(see Appendix A: page 51)</i>	
9. Other pertinent information:	



Phone the healthcare provider if you have any questions about this schedule. This includes questions about the amount of formula, feeding times, and problems with weight gain, etc.

Contact Name: _____
Phone : _____

Giving Tube Feedings

GENERAL INFORMATION:

- **Wash your hands!** Washing your hands can prevent the spread of illness! Washing your hands is one of the most important steps you can take when caring for your child's tube feed.



When washing your hands please make sure you:

- Remove rings and watch. These can trap germs.
- Use warm water and regular soap and rub all parts of your hands and wrists. Friction is the best way to get rid of harmful germs.
- **Wash for 30 seconds.** **Hint:** Sing "Happy Birthday to You" (the whole song) and 30 seconds will have passed.
- Rinse well. Leave the taps running and dry your hands with a clean towel.
- Turn off the taps with the towel.



- Store unopened containers of formula in a dry place at room temperature. Check the expiry date stamped on the container and do not use formula after the expiry date.
- Store opened containers of formula in the refrigerator. Cover the top of the container and label it with the date and the time it was opened. Storing formula in the refrigerator will help to reduce bacterial growth that can cause illness.
- Throw out unused formula in opened containers after 24 hours.
- Throw out any formula that has been open or hanging in a tube feeding bag at room temperature for more than the hang times recommended (See table on page 26).
- Rinse and wash the bag and tubing, see page 27 for instructions on how to do clean up. Equipment that is not carefully cleaned may contaminate the formula and cause illness.



- If possible, the child should be sitting upright in a chair or wheelchair at the table during the feeding and for at least 30 minutes after the feed has finished.



- If feeds are given in bed, make sure that the head of the bed is elevated 30 degrees during the feed and for at least 30 minutes after the feed has finished.
- Flush the feeding tube with water before and after each bolus feeding and when giving medications to prevent a blocked tube. If the child is 3 months or younger, flush with sterile water.
- Experience has shown that flushing the feeding tube with water every four (4) hours during a continuous tube feeding will help to prevent a blocked tube. If the child is 3 months or younger, flush with sterile water.
- **Do not** add fresh formula to formula that is already hanging in the bag.



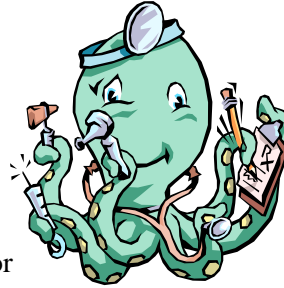
- If using a pump, refer to the instruction booklet given on how to use the pump.

GETTING READY:

Step 1 Prepare a clean work area and wash your hands.

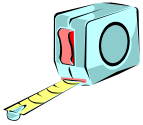
Step 2 Gather the equipment:

- Feeding bag and tube
- Tube feeding formula
- 30 – 60 cc Syringe
- Lukewarm water or sterile water if the child is less than 3 months old
- If needed, a feeding adaptor or connector for low profile devices.
- IV pole, coat rack or hook/nail in the wall
- A pump, if using.
- Other: _____



Step 3 Wash your hands again before touching the equipment and patient/child. Check the stoma for any leaking, skin irritation, infection or swelling. If you notice any problems, refer to *pages 43 & 44*.

Step 4 Measure the feeding tube that is outside of the body and compare it to the length measured before, see *page 4*. If it is shorter, gently pull on it until it is the right length. If it is longer, **DO NOT USE** the tube for feeding. Call the nurse or primary health care doctor.



Step 5 If you are reusing a feeding bag, check that it is clean and does not have any leaks. If the bag smells sour, is cloudy, has a different colour or just looks dirty, throw it away and use a new bag and tubing.

Step 6 Rinse the top of the formula container with water and wipe dry. Shake the container well.

Step 7 Open the container(s) of formula.



- If the container of formula has been in the refrigerator, allow it to stand at room temperature for 15 – 20 minutes before using or warm in a warm water bath. If the formula is too cold, it may cause cramping.
- **DO NOT USE** the **microwave to heat** the formula because this breaks down the proteins.



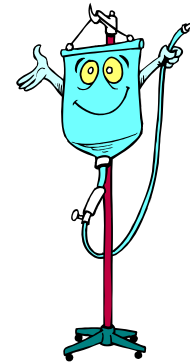
Step 8 Close the clamp on the feeding bag tubing. If using extension tubing, add it to the bottom of the feeding bag tubing.

Step 9 Fill the feeding bag with enough formula to be used within the recommended hang time. Refrigerate unused formula in a clean covered plastic or glass container or covered can. Mark the date and time the container was opened. After 24 hours, throw out any opened formula that has not been used.



Step 10 To prime the tubing (**some infusion pumps will prime the tubing for you**): open the clamp and allow the formula to fill the tubing. Do not fill the drip chamber more than ½ full.

Step 11 When the formula reaches the end of the tube tip, close the clamp. Ask your health care provider how to plan for continuous feeds if that is the schedule that is recommended for feeding your child. (If using some of the pumps, this is not necessary. Refer to the pump instructions).



Step 12 Using an IV pole, coat rack, hook or nail in the wall, hang the feeding bag about 18 inches (46 cm) above the stomach.

Formula Hang Times		
<i>Type of formula</i>	<i>If re-using bags and tubing</i>	<i>If not re-using bags and tubing</i>
Ready to Serve Formulas	Maximum 4 hours	Maximum 8 hours
Formulas prepared from powder or concentrate	Maximum 4 hours	Maximum 4 hours
Formula with additives	Maximum 4 hours	Maximum 4 hours
Fresh Expressed Breast Milk	Maximum 6 hours	Maximum 6 hours
Previously Frozen Expressed Breast Milk	Maximum 4 hours	Maximum 4 hours

MEAL TIME:

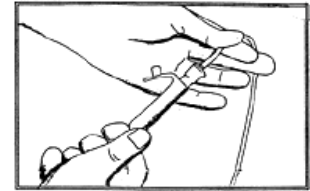
Step 1 The child should be in a comfortable, upright position in a chair or wheelchair. If this is not possible, the child can lie down on a bed with the head of the bed or crib elevated 30 – 45 degrees. With infants, cradling while holding the baby upright in your arms for feeding may work best.



Step 2 Draw up [] ml of lukewarm water into the syringe. Check to see that the feeding tube is clear by flushing it with [] ml of lukewarm water. If the water does not go in, refer to *page 33*.

Step 3 Connect the feeding bag tubing to the adaptor, if used, and then to the feeding tube.

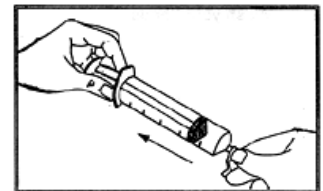
Step 4 Open the clamp on the feeding bag tubing to allow a steady drip. Suggested rate: []. If a pump is being used, refer to the instructions on how to use the pump.



FINISHING UP:

Step 1 After the formula has finished, close the clamp on the feeding bag tubing and disconnect it from the feeding tube.

Step 2 Using the syringe, draw up [] ml of lukewarm water. Use sterile water if your child is less than 3 months of age. Flush the feeding tube. Close the clamp on the feeding tube.



Step 3 First, rinse the feeding bag and tubing with cool clean water. Then, wash the feeding bag and tubing (and adaptor or connector if used) with hot soapy water. Use a bottlebrush to get the corners of the bag to remove old formula and prevent bacterial growth. Rinse well with hot water.

Step 4 Shake really well to remove excess water from the feeding set. The goal is to remove as much water as possible from the inside of the bag. Wrap the feeding set in a clean, dry towel and store it in the refrigerator. Storing the bag and tubing refrigerated will help reduce bacterial growth.



Step 5 After the last feeding of the day, wash and rinse the feeding bag and tubing as described in **Step 3** and **Step 4**. Many families find it convenient to alternate using 2 sets of feeding bags and tubing. While one is being cleaned the other one is ready for use.

You must clean the feeding bag and set AT LEAST once a day.

Step 6 With good cleaning feeding bags and tubing may be changed twice a week.

Never use the bag if it smells sour or is cloudy or “looks dirty”.

If a pump is used, the feeding set tubing may stretch over time and will not infuse the formula at the desired rate. If this happens, replace the bag and tubing set.

Note Well: Current recommendations from the manufacturers state that the feeding set is to be changed everyday. By keeping this equipment extremely clean, it is both practical and economical to change supplies less frequently. Keeping the supplies clean prevents bacterial growth which can cause serious illness. Ask your health care provider for more information.

FEEDING ADAPTORS:

Low profile feeding adaptors and connectors are usually changed every 4 weeks.

Wash adaptors and connectors in the same way as a feeding bag and tubing is cleaned.

SYRINGES:



- At least once a day take syringes apart (separate the barrel and from the plunger) and cleaned in warm, soapy water. Rinse well with hot water.
- Allow syringes to air-dry on a clean surface between uses.
- Change syringes twice a week.

Syringes are changed twice a week.

Giving Medications through a Feeding Tube



GENERAL INFORMATION:

- The tube may be used to give medications. However if the child is able to take medications by mouth, use this route.
- Not all medications can be safely given with a feeding tube. Check with the primary health care doctor or nurse. If possible, give medications by mouth.
- Do not mix medications with the formula.
- **NEVER** mix other medications with antacids or vitamin supplements containing iron, calcium or magnesium.
- Give each medication separately with water flushes between each medication.
- Give medications as directed by the primary health care doctor or pharmacist.
- Use liquid medications when possible to avoid blocking the feeding tube.
- Dilute thick liquid medications such as Phenytoin, Docusate, Lactulose or certain antibiotics with 5 – 10 ml of water.

**If possible,
give
medications by
mouth.**



GIVING MEDICATION:

Step 1 Wash your hands.

Step 2 Gather the following items:

- Medication (liquid or tablet)
- 2 clean syringes: one to check position of the tube and for water flushes, and the other one for medications
- Lukewarm tap water in a large cup (use sterile water if the child is less than 3 months of age)
- Utensil or device for crushing pills

Step 3 If the medication is a liquid, go to **Step 4**. If medication is not liquid read below before going to **Step 4**.

- **If the medication is a tablet**, ask the pharmacist if the medicine can be crushed. If yes, then crush the tablet to a fine powder. Dissolve the powder in one tablespoon of warm water or as directed by your health care provider. If the medication cannot be crushed, ask the pharmacist if it comes as a liquid.
- For a small infant try to use the least amount of sterile water – use just enough to dissolve the powder.

Step 4 Draw up [redacted] ml of lukewarm water into the syringe for water flushes. Use sterile water if the child is less than 3 months of age.

Step 5 Draw up the right amount of prepared medication into the second syringe.

Step 6 Check the position of the feeding tube by measuring the length. If it is shorter, gently pull on it until it is the right length. If it is longer, **DO NOT USE** the tube for feeding. Call the nurse or primary health care doctor.

Step 7 Attach the water-filled syringe to the feeding tube. Open the feeding tube and flush it with [redacted] ml.

Liquid



Tablet

- Step 8** Attach the syringe with medication to the feeding tube and push the medication into the tube.
- Step 9** Draw up ml of water into the water flush syringe and attach it to the feeding tube. Flush the feeding tube.
- Step 10** To give more than one medication, put each medication into a separate syringe and follow **Steps 7-9** for each medication.
- Step 11** Remove the syringe (and tubing adaptor, if used) and clamp the feeding tube.
- Step 12** Wash the syringes and adaptor in warm, soapy water. Separate the plunger from the barrel of the syringe to wash. Rinse with hot water and place them on a clean surface to air-dry.



Flushing well before and after each medication will help to prevent blocking the feeding tube!

A Note About Flushes:

The amount of water used for flushes can quickly add up. This is an important factor with small babies, especially if there are fluid restrictions. Before you leave the hospital decide with your health care provider the amount of water to use for flushes.

Preventing and Solving Problems (Alphabetical Order)

ASPIRATION

Aspiration occurs when stomach contents (formula or water) enters the lungs. It is a very serious problem as it can cause breathing problems and infection.

Signs

Signs of aspiration:

- Coughing and/or choking while given the feed
- A change in breathing pattern to difficult, noisy breathing or rapid shallow breathing
- Wet, gurgly voice
- Pale or bluish lips

Prevention

To prevent:

- Sit upright or raise the head of the bed 30 to 45 degrees during each feeding and for 30 to 60 minutes after the feeding is finished.

If you think aspiration has occurred:

- Stop the feeding right away.
- Ensure the individual is sitting upright and that the airway is clear.
- For babies, it may be helpful to position lying them on their side with their head and neck in a neutral position.
- If the individual does not improve after taking these steps, call an ambulance (911) right away.

BLOCKED FEEDING TUBE

A blocked feeding tube can occur when:

- The tube is not flushed
- Formula is too thick
- Residue builds up in the tube
- Medications are too thick

Prevention

To prevent:

Prevention is the key!

Flush ◆ Flush ◆ Flush

What to Do

- Flush tube with warm water before and after feeds and medications
- Crush all medications to a fine powder and dissolve in a small amount of warm water

If the tube blocks:

- Use a 30 – 60 cc syringe to gently push 20 mls of warm tap water through the tube.
- For infants less than 3 months of age use sterile water and push up to 10ml of warm sterile water through the tube.
- If this does not open the tube, flush with the water and then pull back on the syringe's plunger while it is connected to the tube. Repeat this 3 – 4 times.

**If using warm water does not unclog the tube then try
Pancreatic Enzymes to clear:**

1. Assemble Equipment
 - a. Cotazyme Capsule (pancreatic enzyme)
 - b. Sodium Bicarbonate – 1 tablet (325mg) crushed to a fine powder
OR ½ teaspoon of Baking Soda
 - c. Warm Water or Sterile Water for infants less than 3 months of age
 - d. 60 ml syringe
 - e. small cup
2. WASH hands
3. Draw back as much of the contents of the blocked tube into the syringe as possible.
4. Place the contents of an opened Cotazyme capsule and a crushed Sodium Bicarbonate tablet or ½ tsp of Baking Soda into a cup. Add 10 – 15ml of warm water and dissolve both medications thoroughly.
5. Draw up the dissolved solution into the 60ml syringe and place it into the tube. Clamp off the tube for 15 – 30 minutes. Milk the tube to get the solution as close as possible to blocked area.
6. Unclamp the tube and attempt to flush again with warm water and firm pulling and pushing action. If the tube does not become clear, repeat above steps, leaving the solution for up to one hour.
7. If two attempts do not clear the tube then it most likely will need to be replaced.
 - If this does not work, contact the nurse or primary health care doctor for further instructions.

CONSTIPATION

Constipation means that the bowel movements are hard and difficult to pass and occur less often. Each child has his or her own pattern. Some children have one or more bowel movements each day. Others have a bowel movement once every few days. Infants and children who are on tube feeds may not have the same pattern as children who eat orally.

Prevention

To prevent:

- Make sure the recommended amount of water flushes are given.
- Encourage daily physical activity.

If constipation occurs:

- Ask your health care team contact if :
 - a different formula or more water or diluted prune juice may be needed?
 - any medications might be the cause?
 - medications might be needed to help?

Contact the nurse, dietitian or primary health care doctor if:

- Bowel movements are uncomfortable – they hurt.
- Tube feedings are causing bloating, feeling full.
- No bowel movement for more than 3 – 4 days.
- A small amount of bleeding with bowel movements.

DEHYDRATION

Dehydration means that the body does not have enough fluids.

Dehydration can be caused by:

- Vomiting
- Diarrhea
- Sweating – this can be due to hot weather and/or fever

Signs

Signs of dehydration include:

- Dry, sticky tongue
- Sunken eyes
- Cracked, dry lips
- Thirst
- Small amounts of dark yellow urine
- Fewer wet diapers
- Depressed or sunken fontanelle (soft spot on the head) of infants

Prevention

To prevent:

- Make sure that the recommended amounts of formula and water flushes is given each day.

If you think dehydration has occurred:

- Babies can become dehydrated very quickly. If you think your baby is dehydrated then contact your health care provider immediately. Talk with the doctor or nurse before increasing amount of water flushes.
- Increase the amount water flushes given before, during and between feedings.
- Contact the primary health care doctor or nurse if the symptoms continue for more than [redacted] hours.

DIARRHEA

Diarrhea is frequent, watery bowel movements. Check for signs of dehydration and follow guidelines. See *page 37*.

Prevention

To prevent:

- Give the formula at the recommended rate.
- Make sure all tube-feeding supplies are clean.
- Wash your hands well before giving the tube feeding.
- Make sure the instructions on storing the formula are followed. See *page 25*.
- Do not hang formula for more than the recommended time (see *page 26*).
- Do not use formula that has been in the refrigerator for more than 24 hours or that has past the expiry date on the container.
- Ensure the formula is at room temperature before giving.

If diarrhea occurs:

- Call the nurse or primary health care doctor if there are more than 5 watery bowel movements in 24 hours. He/She may suggest a temporary change in the tube feeding for a few days.
- If the diarrhea is **severe** – large amounts of loose stools every 1 to 2 hours, call the primary health care doctor if it continues for longer than:
 - 4 hours in an infant under 3 months of age
 - 8 hours in an infant age 3 – 6 months
 - 1 – 2 days in a child age 7 months to 4 years



Check the child's temperature to make sure he or she is not ill. **A fever is an oral temperature above 37.4°C (99.4°F).**

continued...

- Call the primary health care doctor whenever :
 - the temperature is 38.5 C (101.3 F) or higher, or
 - the temperature is between 37.4 C (99.4 F) and 38.5 C (101.3 F) and the child has had diarrhea for more than 2 days

- Keep a daily record of the number of bowel movements and other symptoms and when they occur.

- If your child is receiving chemotherapy or is neutropenic and develops a fever, then contact your doctor or oncologist on call (even if there are no skin signs).

- Try a slower feeding rate. If the feedings are not tolerated at the recommended rate after 48 hours, call the physician or health care provider.

- Ask the health care provider if:
 - a different formula might help?
 - any of the medications taken might be causing diarrhea.



FEEDING TUBE FALLS OUT

Prevention

To prevent:

Follow the instructions on *page 10* to help keep the tube in place.

If the tube falls out:

G – Tubes:

- Cover the stoma with a clean gauze.
- If this is a brand new G tube and has been in for less than 6 weeks, go to the nearest hospital emergency department as soon as possible. The tube needs to be replaced by a health care professional before the stoma shrinks closed.
- If the tube has been in for more than 6 weeks, there is a need to replace the tube as soon as possible.
- If you have been taught to reinsert the tube, follow the instructions in Appendix E, *page 56*.

J – Tubes and G-J Tubes:

- If this is a G-J tube you need to insert your replacement G tube.
- If you have been taught to reinsert the tube, follow the instructions in Appendix E, *page 56*.
- If your child can tolerate food or medications into their stomach, then use this tube until you can make an appointment with the radiologist to replace the G-J tube.
- If your child cannot tolerate food or medications through the replacement G tube then you will need to take your child to the hospital for IV fluid and medications.

FLUID AROUND THE TUBE

Prevention

To prevent:

- Make sure the correct flow rate and volume of formula is given.
- Make sure the tube is securely taped to prevent pivoting action or pulling on the stoma. Do not tape low profile devices.
- Check for granulation tissue around the tube.
- Make sure the feeding tube is not blocked – flush with water frequently.

If leaking occurs:

Gastrostomy or Jejunostomy Tubes (PEG, MIC or J –tube):

- Check to see if the tube is blocked, the stoma is larger or the tube has moved in or out – measure the tube. Call the nurse or primary health care doctor for advice.
- If the tube has a balloon internal bumper (MIC tube or MIC-KEY) and you have been taught to do so, check that the balloon is properly inflated.
- Try to keep the area as clean and dry as possible, if necessary, use zinc oxide or gauze to protect the skin around the stoma.

Low Profile Device (Bard Button; MIC-KEY):

- Check to see if the tube is blocked, the stoma is larger or if the tube has moved in or out.
- Check once a week to make sure the balloon has enough water.
- If your child has a balloon internal bumper type tube (MIC tube or MIC-KEY), and you have been taught to do so, check that the balloon is properly inflated with ml of sterile water.

FLUID LEAKING THROUGH THE TUBE

Sticky, sugar containing formula or medications can interfere with the one way (anti-reflux) valve. Flush frequently with water through the adaptor.

Prevention

To prevent:

Low-profile devices:

- Do not leave the adaptor or connector attached after the feed as it keeps the valve open.
- Always use the feeding adaptor. Never put a syringe directly into the feeding tube. The pressure from the syringe can break the anti-reflux valve.

If leaking occurs:

Bard Button:

- The anti-reflux valve in the button may be stuck open or the valve may be broken.
- Using the adaptor, flush the tube several times using warm water to try to unstick the anti-reflux valve.
- If this does not work, gently insert a #8 or #10 French Foley catheter or decompression tube into the shaft of the button to see if it can move the valve back to the closed position. The anti-reflux valve should make a popping sound when closing and the leaking should stop.
- Repeat this several times.
- If this does not stop the leaking, the valve may be broken and the button will need to be replaced.
- Call your nurse or primary health care doctor to help you arrange this.

MIC-KEY:

- Using the adaptor, flush with warm water using a 30 ml slip-tip syringe.
- If this does not stop the leaking, the device may need to be replaced. If you have been taught to replace this device, refer to *page 56*. If not, call the nurse or primary health care doctor.

GRANULATION

"Granulation" tissue or sometimes called proud flesh is a type of scar tissue that may form around the tube. This red, raised tissue is the body's reaction to the tube and is very common in some children.

Granulation is a nuisance. It can rub on clothing and bleed easily and often leaks a sticky yellow fluid. This is not dangerous.

Treatment

If granulation tissue occurs:

- Call the nurse or primary health care doctor to ask about **silver nitrate stick**, that can help to remove the granulation tissue. When touched by the silver nitrate stick, the granulation tissue turns grey or black, then becomes crusty and falls off.

Steps for using silver nitrate sticks.

Note: Repeat the following steps once each day for 7 days:

- Step 1** Put a layer of Petroleum jelly (Vaseline) on the healthy skin around the piece of red skin before using the silver nitrate stick. Be careful not to touch normal, healthy skin with the stick as it will injure the healthy skin.
- Step 2** Gently touch the silver nitrate onto the piece of red skin.
- Step 3** Protect clothing from being stained by the silver nitrate (can turn black) by putting a small gauze square over the area and taping it.

- **If there is no improvement after 7 days, call the nurse or primary health care doctor.**

Skin INFECTION Around the Tube or Stoma Site

Signs

Signs of skin infection may include:

- Skin is fiery red, hot and swollen
- Discharge from the stoma is thick and cloudy with a white or yellow-green colour
- Skin hurts a lot and all the time
- Fever (**temperature above 37.4 °C or 99.4 °F**)
- Stoma area smells bad

What to do

If a skin infection occurs:

- Call the primary health care doctor.
- Soak the skin around the stoma 4 times a day for 5 to 10 minutes each day.

10 Steps for soaking the skin around the stoma:

How to make Salt Water

1. Boil 1 cup of water for 10 minutes.
2. Add ½ teaspoon of salt to the boiled water and let cool.

Step 1

Gather the equipment needed:

- 3 sterile gauze squares (2 packages)
- clean bowl
- Salt water (see recipe in box) or Normal Saline (sterile salt water).

Step 2

Clean the work surface.

Step 3

Wash your hands.

Step 4

Pour the warm salt water into the clean bowl.

Step 5

Open the package of gauze and drop into the bowl of salt water.

Step 6

Lift one wet gauze and place over the stoma area. Leave it there for 5 minutes.

Step 7

Repeat **Step 5** another 3 times using a new gauze square each time.

Step 8

Let the skin air dry.

Step 9

If the primary health care doctor has ordered an antibiotic cream, put it on now.

Step 10

If there is a lot of leaking around the tube, cut a gauze square to fit around the tube. Use a small amount of tape to keep the dressing in place.

Skin IRRITATION Around the Tube or Stoma Site

Signs

Signs of skin irritation may include:

- The skin is redder than normal and raw looking
- There is a watery, thin discharge
- The skin is tender to touch
- Skin irritation may be caused by leakage around the tube.

Prevention

To prevent:

- Make sure that the tube is stable so that it does not move around
- Gently pull on the tube to ensure that the balloon/end of the tube is up against the stomach wall. If you have been taught to do so, check the amount of water in the balloon.

If a skin irritation occurs:

- Keep the area clean. Wash with mild soap and warm water 3 – 4 times each day and pat dry.
- Expose the skin to air for about 30 minutes at least 3 times a day.
- Ensure the tube is secure with tape and there is no pivoting action of the G-tube.
- If there is a lot of leaking around the tube, cut a gauze square to fit around the tube. Use a small amount of tape to keep the dressing in place.
- Call the nurse or primary health care doctor if this does not clear up within 3 days. Use of a cream may be suggested.

STOMACH FULLNESS/BLOATING

Stomach fullness and bloating may be caused by:

- Feeding is given too quickly
- Swallowing air

Signs

Signs of stomach fullness/bloating may include:

- The child may have pain or discomfort in the abdomen or be restless and cry.
- A child who is unable to communicate may vomit or burp.

Please note:

- Sometimes a bloated, full feeling may indicate constipation.
- See *page 35* for tips on constipation.

Prevention

To prevent:

- Follow the feeding guidelines for the type of formula, rate and schedule

If fullness or bloating occur:

- Decrease the feeding rate.
- Stop the feeding for 1 – 2 hours and then restart the feeding at a slower rate. Slowly increase the rate to the highest rate that is comfortable. If the usual rate cannot be reached, call the health care provider.
- Try to decompress the stomach before feeding. Attach the outside only (barrel) of a 30 ml syringe to the end of the feeding tube or, for the low profile devices, attach it to the adaptor. Hold the syringe barrel above the stomach to allow gas to escape for about 5 to 20 minutes. If stomach juices come into the syringe, allow the juices to flow back, by gravity, into the stomach to prevent the loss of electrolytes.

VOMITTING

Vomiting or gagging may be caused by:



- Stomach is too full
- Feeding is given too quickly
- Illness

Prevention

To prevent further vomiting:

- Start feeding slowly. If your child tolerates the feed, slowly increase the rate to desired rate.
- Position the child in a sitting position in a chair or in a wheelchair or with the head of the bed elevated.
- Allow a quiet time after feeds.
- Vent the tube or burp the child before, during and/or after the feeding. Try to decompress the stomach before feeding.
 - Attach the outside only (barrel) of a 30 ml syringe to the end of the feeding tube or, for the low profile devices, attach it to the adaptor.
 - Hold the syringe barrel above the stomach to allow gas to escape for about 5 to 20 minutes.
 - If stomach juices come into the syringe, allow the juices to flow back, by gravity, into the stomach to prevent the loss of electrolytes.
- When flushing the tube, do it slowly.
- If vomiting occurs during a feed, stop the feed. If the child is lying down, turn the head to the side or have them sit up.
- If the vomiting continues and the child seems ill or has a fever, call the nurse or primary health care doctor.

Who to Contact with your Questions & Concerns

Questions Or Concerns About	Contact	
Weight:		<ul style="list-style-type: none"> • Dietitian • Nurse • Primary health care doctor
Tube feeding supplies:	<ul style="list-style-type: none"> • Nurse • Dietitian • Community Liaison Nurse (AHP) 	
Formula:	<ul style="list-style-type: none"> • Dietitian • Primary health care doctor 	
Feeding tube or feeding tube site care:	<ul style="list-style-type: none"> • Nurse 	
Skin problems:	<ul style="list-style-type: none"> • Nurse • Primary health care doctor 	
Tube Feeding at School or Daycare:		<ul style="list-style-type: none"> • Nursing Support Services
Feeding pump:	<ul style="list-style-type: none"> • Pump rental store or company • At Home Program 	
Oral stimulation during tube feeding:	<ul style="list-style-type: none"> • Occupational Therapist • Speech-Language Pathologist 	
Oral Feeding:	<ul style="list-style-type: none"> • Dietitian • Occupational Therapist • Speech-Language Pathologist • Primary health care doctor • Nurse • Feeding Team 	



Telephone Numbers

Contact	Name	Phone Number
Dietitian		
Nurse		
Nursing Support Services		
Primary health care doctor		
Occupational Therapist		
Speech-Language Pathologist (SLP)		
Nurse Clinician		
Distribution Center (AHP/HEN)		
Other:		

Appendices

Appendix A: Monitoring Progress

Date	Weight	Feeding Schedule	Concerns/Questions	What to Do?

Date	Weight	Feeding Schedule	Concerns/Questions	What to Do?

Appendix B: Ongoing Questions & Concerns

“How to make the best use of clinic visits or appointments with your child’s health care team.”

You will have more questions and concerns come up over time. Here are some tips on how to make sure that you have them answered.

At home:

- Keep a journal of your questions and concerns.
- If you want to talk with a certain person at the clinic or office, call ahead to make a set time.
- Ask a family member or friend to come with you to take notes, offer support, or help care for your child while you talk to the health care team.



At the clinic or appointment:

- Ask your most important questions early in the appointment
- Take notes to help you remember what was said.
- Let the team know as much as you can about your thoughts on your child’s health and how your child is doing with the tube feeding – you know your child best!
- If you do not understand the medical words used – ask.
- Sometimes a picture can help you to understand what is being said – ask for one.
- Repeat what you think was said to you.

Appendix C: List of Terms

Abdomen	contains the stomach, small and large intestines, liver, gall bladder, spleen, pancreas, and bladder
Aspiration	occurs when fluid enters the lungs
Abscess	a localized collection of pus in a tissue or body part resulting from the invasion of bacteria
Decompression tube	a device which allows air/fluid to escape (venting) from the stomach via a gastrostomy tube
Gastric decompression	release of air trapped in the stomach
Gastric outlet obstruction	blockage at the end of the stomach
Gastric tube (gastrostomy tube, G-tube)	a feeding tube that supplies food directly into the stomach through a permanent surgical opening (gastrostomy) made into the stomach
Gastro-jejunal tube (GJ tube)	a feeding tube that passes through the stomach via the gastrostomy into the jejunum.
Granulation tissue (proud flesh)	naturally occurring scar tissue that forms around the tube
Gavage	feeding by a tube passed into the stomach
Ileus	An intestinal obstruction or blockage
Jejunal tube (j-tube)	a feeding tube that supplies food directly into the small intestine through a surgical opening (jejunostomy) made into small intestine
Jejunum	the second portion of the small intestine (small bowel)
Laparoscopy	surgical procedure that explores the abdomen using a type of camera called a laparoscope
Laparotomy	the surgical opening of the abdomen

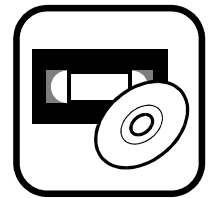
Nissan fundoplication	An operation that is used in the treatment of stomach acid reflux into the esophagus
Peristomal	skin area around the stoma
Pyloroplasty	this is an operation where the pylorus muscle is partially divided allowing the food to move more easily from the stomach to the small intestine
Reflux	backward flowing of a substance (e.g. return of fluids to the mouth from the stomach)
Roux en y	surgical procedure that takes a portion of the jejunum and creates a limb that forms the stoma for the jejunostomy tube
Stoma	an artificial opening

Appendix D: Additional Resources for Families & Caregivers

Books



Videos



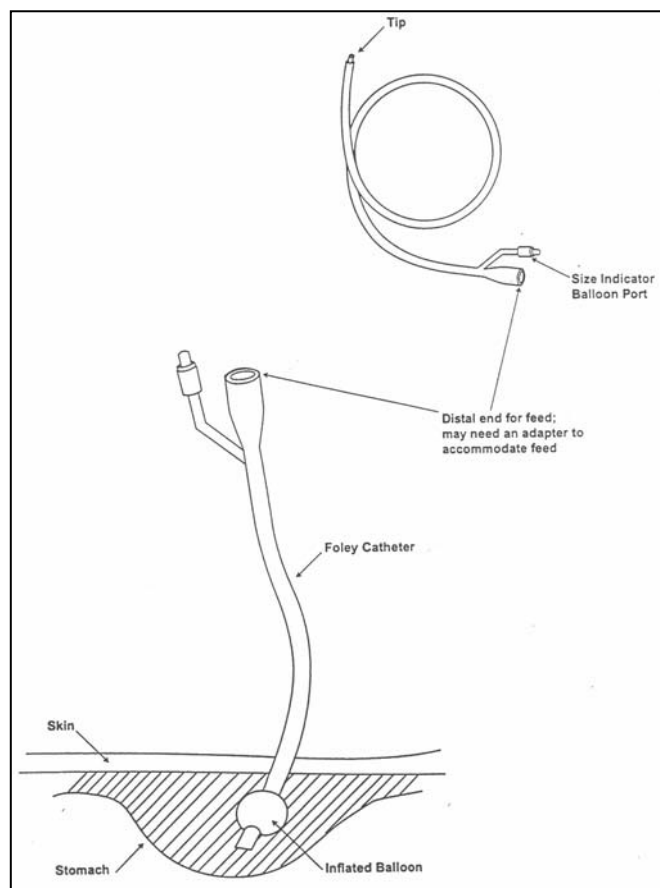
Websites



Appendix E: Reinserting a Gastrostomy Tube (G-Tube)

GENERAL INFORMATION:

- The PEG tube or Bard button low profile device cannot be reinserted. Instead, use the Foley catheter given to you by the hospital.
- Foley catheter, MIC tube or MIC-KEY can be reinserted as follows:



- Check the balloon for leaks by inflating the balloon with 5 ml of sterile water. If no leaks, deflate the balloon and proceed to inserting the tube as described below.
- If there are leaks, throw away the tube and check the balloon on a new tube.
- If there are no leaks, remove the 5ml of water from the balloon and insert the tube as described below.

Figure 10: Foley Gastrostomy Tube

REINSERTION:

Step 1 Wash hands well and gather the following equipment:

- feeding tube or Foley catheter
- tape
- 5 ml syringe – to inflate the balloon
- 5 ml water – to inflate the balloon
- measuring tape (if a balloon-type catheter is used)
- water-soluble lubricant
- tape measure

- Step 2** Draw up 5 ml of water into the syringe.
- Step 3** Check the balloon on the new feeding tube before putting it into the stoma by inflating it with the water.
- Step 4** Deflate the balloon by pulling the water back into the syringe.
- Step 5** Moisten the end of the tube with water or a water-soluble lubricant (for example, K-Y jelly) as it makes the tube go in easier.
- Step 6** Insert the new tube about 2 inches into the stoma.
- Step 7** Inflate the balloon with the 5 ml of water in the syringe. Remove the empty syringe from the tube.
- Step 8** Gently pull on the tube so it is snug against the stomach wall.
- Step 9** If a catheter is used, measure the length of the catheter from the stoma to the end and record the length. Put a mark on the tube where it comes out of the body.
- Step 10** Clean and dry the skin. Tape the tube to the skin to secure.
- Step 11** Check the placement of the tube by withdrawing stomach contents, allow the contents to flow back into the stomach.
- Step 12** If unable to withdraw stomach contents, reposition the person and try again. If no stomach contents, wait ½ hour and try again. If you are not sure that tube is in the stomach, do not use. Call the nurse or primary health care doctor.

Appendix F: Reinserting a Jejunostomy Tube (J-Tube)

GENERAL INFORMATION:

- If using a Foley catheter as a jejunostomy tube, **DO NOT** inflate the balloon on the catheter as it may block the small bowel causing an obstruction.
- Never force the tube. If it is difficult to insert, stop and go to the nearest hospital since repeated tries with force may put a hole in the small bowel.

REINSERTION:

Step 1 Wash hands well and gather the following equipment:

- feeding tube
- tape
- measuring tape
- water-soluble lubricant

Step 2 Moisten the end of the tube with water-soluble lubricant (for example, K-Y jelly) as it makes the tube go in easier.

Step 3 Insert the new tube about 2 inches into the stoma or as per instructed. Tape the tube securely to the stomach.

Step 4 Measure the length of the catheter from the stoma to the end and record the length. Put a mark on the tube where it comes out of the body.

Step 5 Phone your nurse or primary care doctor to help make arrangements to have the tube replaced.

References

1. Alberta Home Nutrition Support Services (2000). Nasogastric Tube Feeding Your Child: A Resource Booklet for Families. Capital Health Region.
2. Anderton, A. & Nwoguh, CE. (1991). Re-use of enteral feeding tubes-a potential hazard to the patient? A study of the efficiency of a representative range of cleaning and disinfecting procedures. Journal of Hospital Infection, 18, 131 – 138.
3. Anderton, A. & Aidoo, KE. (1990) The effect of handling procedures on microbial contamination of enteral feeds: A comparison of the use of sterile vs non-sterile gloves. Journal of Hospital Infection, 17 (4): 297-301.
4. Aneiros, S & Rollins, H. (1996). Home enteral tube feeding. Community Nurse. 28-33.
5. BC Women's and Children's Hospital (1998). Gavage/Enteral Feeding (Nasogastric, Gastrostomy and Jejunal Tube Feedings) for Children and Infants. Nursing Policy and Procedure Manual. Policy: NG001.
6. Brooks, L (2002) Clearing Occluded Feeding Tubes: Moving from Ginger Ale to Enzymes (or taking the "Cozyme Challenge") Practice – Dietitians of Canada Issue #20:8
7. Campbell, SM. (1995). Preventing Microbial Contamination of Enteral Formulas and Delivery Systems, Ross Medical Nutrition Systems.
8. Children's Hospital of Eastern Ontario. (1998). Home Enteral Feeding Programme: General Guidelines.
9. Children's Hospital of Eastern Ontario. (1998). MIC-KEY Skin Level Feeding Device: Teaching Guide.
10. Children's Hospital of Eastern Ontario (1998). Gastrostomy Button Feeding: Teaching Guide.
11. Children's Hospital of Eastern Ontario (1998). Gastrostomy Tube Feeding: Teaching Guide.
12. Children's Hospital of Eastern Ontario (1998). Jejunostomy Tube Feeding: Teaching Guide.
13. DaSilva, B. (2000). Summary of Tube Feeding Practice. Member of the Vancouver/Richmond Regional Tube Feeding Committee.
14. Frankel, E et al, (1998) Methods of restoring patency to occluded feeding tubes Nutrition in Clinical Practice 13:129-131
15. George Pearson Centre (2000). Guideline for Gastrostomy Care and Management.

16. Grant, M.C. & Martin. S. (2000). Delivery of enteral nutrition. AACN Clinical Issues, 11 (4), 507-516.
17. Grunow, JE, Cristenson, JC, & Moutos, D. (1989). Contamination of enteral nutrition systems during prolonged intermittent use. Journal of Parenteral and Enteral Nutrition, 13 (1), 23 – 25.
18. Guenter, P. & Silkroski, M. (2001). Tube Feeding: Practical Guidelines and Nursing Protocols. Maryland: Aspen Publication.
19. Health Canada (1998). Infection Control Guidelines: Hand Washing, Cleaning Disinfection and Sterilization in Health Care. Canada Communicable Disease Report: Supplement. Volume 24S8.
20. HSCL (1996). Module 8 – Gastrostomy Care. HSCL Resource Guide.
21. Kemper, D.W. (2000). BC Health Guide. Idaho: Healthwise Publications.
22. Lee, C.H., & Hodgkiss, I.J. (1999). The effect of poor handling procedures on enteral feeding systems in Hong Kong. Journal of Hospital Infection, 42, 119-123.
23. Matergio, D (2002) Backing up our Practice with a Simple Study Practice – Dietitians of Canada 19:5
24. Oie, S. & Kamiya, A. (2001). Comparison of microbial contamination of enteral feeding solution between repeated use of administration sets after washing with water and after washing followed by disinfection. Journal of Hospital Infection, 48, 304-307.
25. Patchell, C. J., Anderton, A., Holden, C., Macdonald, A., George, R. H., Booth, I. W. (1998). Reducing bacterial contamination of enteral feeds. Archives of Disease in Children. 78, 166-168.
26. Ross Products Division (1999) Best Practice Guidelines for Tube Feeding: A Healthcare Professional Manual
27. Smarszcz, RM, Proicou, GC, & Dugle, JE. (2000). Microbial contamination of low-profile balloon gastrostomy extension tubes and three cleaning methods. Nutrition in Clinical Practice, 15 (3), 138-142.
28. Swalwell-Franks, A. (2001). Common Tube Feeding Complications Handout for Families.
29. Taylor, L.J. & Fona, S.H. (1997). Caring for the patient with a gastrostomy/jejunostomy tube. Home Care Provider, 2 (5), 221-224.
30. Thompson, L. (1995). Taking a closer look at percutaneous endoscopic gastrostomy. Nursing, April, 62 – 63.
31. Vancouver Hospital & Health Sciences Centre (2001). Tube Feeding at Home: A Guidebook for Patients, Families and Caregivers.

32. Vancouver/Richmond Regional Tube Feeding Committee (2001). Changing Feeding Tubes: When to Replace Gastrostomy and Jejunostomy Tubes.
33. Vines, S., Arnstein, P., Shaw, A., Buchholz, S., & Jacobs, J. (1992). Research utilization: An evaluation of the research related to causes of diarrhea in tube patients. Applied Nursing Research, 5 (4), 164 – 173.
31. Washington State Department of Health (2002) Nutrition Interventions for Children with Special Health Care Needs 2nd Edition

Information Compiled by:

Linda Yearwood, RN, MSN

Sincere thanks to the many contributors and reviewers who gave so generously of their time.

The following groups were involved in completing this project:

C&W Nutrition Committee
Feeding Team at Sunny Hill
Gastroenterology
Nursing Support Services
Nutrition and Food Services
Occupational Therapy
Pediatric Surgery
Special Care Nursery

Financial Assistance Gratefully Provided by:

Sunny Hill Health Centre for Children Auxiliary