

Caring for a Child with a Feeding Tube

www.childrenswi.org/gtube



Kids deserve the best.



Contents

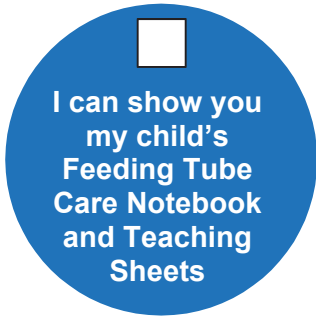
Chapter 1: Introduction	1-1
The Tube Feeding Care Notebook	1-1
When do I use the care notebook?.....	1-1
The journey home	1-1
Tube Feeding Stepping Stones	1-2
Letter from a mom.....	1-3
A guide for parents.....	1-4
Understanding feeding tubes	1-4
What is a gastrostomy tube (G-tube)?	1-4
What is a jejunostomy tube (J-tube)?.....	1-4
Why does my child need a feeding tube?	1-4
How is the feeding tube put in?.....	1-5
Types of feeding tubes.....	1-5
Types of G-tubes	1-6
Gastrojejunal tubes (GJ-tube).....	1-6
Questions you may have.....	1-7
Key points.....	1-7
Chapter 2: Daily care	2-1
What to expect after the feeding tube is put in	2-1
Pain.....	2-1
Activity	2-1
Drainage.....	2-1
Redness	2-1
Tube and skin care	2-2
Cleaning the skin.....	2-2
Other information.....	2-2
Bathing and swimming	2-3
Dressings	2-3
Securing the tube.....	2-3
Tension loop.....	2-4
Bolster to secure long tubes	2-5
Other ways to secure all types of tubes	2-5
Key points.....	2-5
Chapter 3: Feeding, flushing, venting, and supplies	3-1
Feeding your child with a tube.....	3-1
Other thoughts	3-1
Formulas	3-2
Bonding time while tube feeding babies	3-2
Toddlers, older children and teens	3-3
Feeding your child.....	3-3
Water and vitamins	3-3
Oral feeding.....	3-4
Oral hygiene.....	3-4
Tube feedings and schedules	3-4
Methods of feeding.....	3-5

Continuous drip feeding.....	3-5
Feeding using a pump.....	3-5
Giving continuous or drip feedings.....	3-6
Giving bolus feedings.....	3-7
Combination drip and bolus feeding.....	3-7
Feeding through a GJ-tube.....	3-8
Flushing.....	3-8
GJ-tubes.....	3-8
Venting the G-tube.....	3-9
When and how should I vent?.....	3-9
Supplies.....	3-10
Home supply company.....	3-10
Cleaning and changing the supplies.....	3-10
Key points.....	3-11
Chapter 4: Medicines.....	4-1
Important medicine information.....	4-1
Giving medicine.....	4-2
How to give medicine through a tube.....	4-2
Key points.....	4-3
Chapter 5: Preparing for home.....	5-1
When and how to call the team managing your child's feeding tube.....	5-1
Care team members.....	5-1
Contacting your care team.....	5-2
Clinic visits.....	5-2
First tube change.....	5-3
Common problems.....	5-3
Granulation tissue.....	5-4
Emergencies.....	5-6
Things that need medical attention right away.....	5-6
Guide to concerns.....	5-7
Chapter 6: Resources.....	6-1
Parent to parent.....	6-1
Family support.....	6-3
Financial.....	6-4
Nutrition resources.....	6-5
School and therapy.....	6-6
Transportation.....	6-6
Internet resources.....	6-7
Chapter 7: References.....	7-1
GJ-tube plan of care.....	7-1
Bolster dressing.....	7-3

Glossary

Chapter One:

Introduction



I can show you
my child's
Feeding Tube
Care Notebook
and Teaching
Sheets

The Tube Feeding Care Notebook

This Care Notebook will help you learn new things. It can be used at home if you need to remember how to care for your child's feeding tube. You can also use it to write down your questions and take notes.

Important topics are divided into sections so you can find them easily. You can also find meanings of words that are new to you in the back of this notebook. This is called a glossary.

When do I use the care notebook?


Keep it with you when you are learning in the hospital. Then use it at a home as needed. If you have a concern or question, look in the Care Notebook to decide if you need to call the doctor.

The journey home

The Stepping Stones page is a map. The nurses will check off the stones as you tell or show them that you understand each step.

This will help you feel confident when taking care of your child's feeding tube.

You can see this information on a mobile friendly website <https://childrenswi.org/gtube>. There are also videos that show you how to care for the skin and tube.



I can tell you
where to find
the G-tube
online videos

Tube Feeding Stepping Stones to Home for _____



What I need to know and do to get us ready to go home.

Start

I can show you my child's G-tube Care Notebook and Teaching Sheets

I can tell you where to find the G-tube online videos

I can tell you ways to keep my child comfortable

I can show you how to clean the site

I can show you how to put a dressing on the site and tell you when it's needed

I can show you how to give a water flush and tell you why my child needs one

I can show you how to feed my child through the tube

I can show you how to secure the tube and tell you other ways too

I can show you how to vent the tube and tell you when it's needed

I can tell you what to do if there is granulation tissue

I can tell you what to do if the site is red

I can show you how to give medicine through the tube

I can tell you how to order supplies for use at home

I can tell you what to do if the tube falls out or is not working

I can tell you about when my child will have their first tube change

I can tell you who to call if I have a concern

We are ready to go home!

Finish



Letter from a mom

Dear friends,

You are most likely getting this notebook because someone you love has or will be getting a gastrostomy tube (G-tube). G-tubes are used for different reasons. Often it is for feeding. Feeding someone you care for can bring many different feelings. You may feel relief, sadness, anger, hope and more.

As a parent of a child with a G-tube, I was uneasy at first. But I was hopeful that my child would do better with the tube. There were times that I struggled and felt sad. At some point I decided to make the best of this way of feeding. I got used to the tube feedings as part of our child's care. Once I did, they became less stressful. Parents are all different and the amount of time it takes to come to terms with the tube will be different.

You may have lots of questions about how to fit tube feeding into your family life and how to keep their child's life as normal as possible. This notebook will answer many of your questions. Another thing that helps is talking to other parents who have a child with a G-tube. Parents who have been down this road can be a great support. They might share medical advice. Talk about it with your child's doctor first, before making any changes in your child's care.

Please know that whether your child's G-tube is short- or long-term, you are not alone. Many of us have been through this and are more than willing to talk with you. Let your care team know if you would like to talk with another parent or if you learn something that could help other parents.

Warmly,

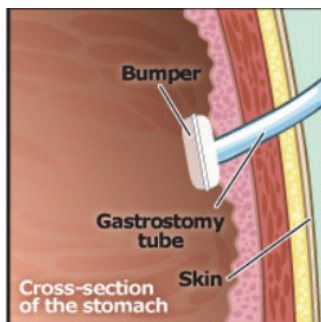
Julie T.

A guide for parents

Before your child goes home after getting a feeding tube, you will be able to:

- feed your child through the tube.
- give your child any medicines through the tube.
- take care of the tube and skin around the tube.
- know how to manage some common problems and know who to call for help.

Understanding feeding tubes

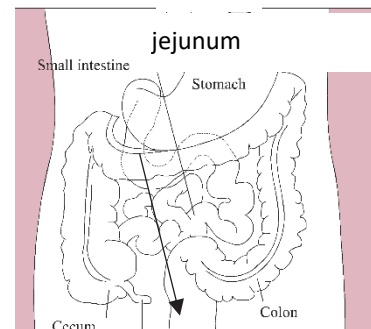


What is a gastrostomy tube (G-tube)?

A gastrostomy tube is a small tube that goes through the skin and muscle into the stomach. It is also called a G-tube. The opening can be called a stoma, site, or tract.

What is a jejunostomy tube (J-tube)?

A jejunostomy tube is placed into a part of the small intestine called the jejunum. It is called a J-tube. The jejunum is where food goes when it leaves the stomach.



Credit: William Crochot US PD picture., Public Domain,
<https://commons.wikimedia.org/w/index.php?curid=1521879>

Why does my child need a feeding tube?

A feeding tube is a safe way to feed your child because it stays in place all the time. It is clamped (closed off) when it is not being used. Some children may be able to eat by mouth and use the feeding tube only when needed. Other children can only be fed through the tube. This all depends on the reason for your child's feeding tube. Your child's doctor will tell you the reasons for a feeding tube.

Some reasons why your child may need a feeding tube:

- Cannot take enough food by mouth to grow and develop.
- Has a hard time sucking, swallowing or eating.
- Has a problem with reflux, or has a metabolic or breathing problem.

Some things that the tube can be used for:

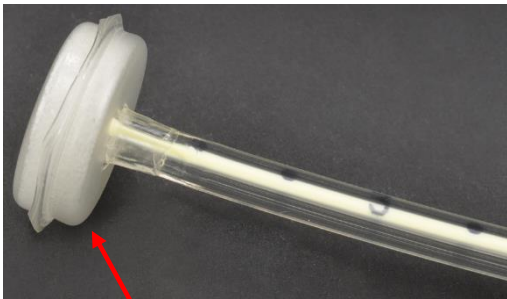
- Giving liquid food.
- Giving medicines.
- Getting extra air out of the stomach, like a burp. This is called venting.

How is the feeding tube put in?

A feeding tube is most often placed in the operating room. Your doctor will tell you how it will be done.

Types of feeding tubes

All feeding tubes have either a balloon or small bumper on the end, which is inside the stomach. This helps keep the tube in place.



Bumper



Balloon
(filled with water)

Ask your child's nurse for a teaching sheet that explains the type of tube for your child.

Types of G-tubes

Your child will start with one type of tube. The type of tube may be changed later to meet your child's needs.



Long tubes

This may be needed in the beginning for a short time. Some may have a balloon, while others may have a bumper.

It is often replaced with a button type of tube.

Button tubes

This is a short tube that is close to the skin on the belly. It is held in place by a balloon.



Gastrojejunal tubes (GJ-tube)

Some children cannot handle food in their tummy or their stomach has a hard time breaking down the food. They may need to be fed past the stomach into their intestines.

To do this, the tube will be changed from the G-tube to a GJ-tube. This lets you feed into the small intestines. Sometimes, this may be needed for only a short time. Your child's doctor will talk to you if this is needed.

If your child does have a GJ-tube, you will get special instructions on how to use these tubes. See References: GJ-tube Plan of Care.

Questions you may have

How long will it take for the skin to heal?

After surgery, your child will have some pain at the site. The site is most painful for the first couple of days after surgery. The pain gets better each day. Most children are better within 2 weeks.

It is common to have some blood at the site. There will be less blood as the site heals.

The tract is the tunnel from the skin to the stomach. The tract takes about 6 to 12 weeks to heal from the outside of the belly to the inside of the stomach.

While the tract is healing, it is important to care for the skin around the site. In Chapter 2 you will learn how to:

- clean the site.
- use a dressing.
- keep the tube secure.

Once the tract is healed, your child's tube can be changed.

You will not get a spare tube at home until the tube is changed for the first time. After the tube is changed, you will be taught how to change it at home.

Will my child have a feeding tube forever?

This will depend on the reason for your child's feeding tube. It may be needed forever. It may be needed only until your child can eat enough food by mouth to grow.

Who will be a part of my child's care while in the hospital?

- Nurse
 - G-tube nurse
 - Surgeon or gastroenterologist
 - Case Manager – helps arrange for feeding and tube supplies needed for home.
 - Dietitian – helps with feeding plan for home.
- } help care for your child and their feeding tube.

Key points

- There are different kinds of feeding tubes.
- It is important to take good care of the stoma while it is healing.
- You will learn how to care for your child's new tube. It may be scary at first, but you will get really good at it.

Chapter Two: Daily care

What to expect after the feeding tube is put in



Pain

After surgery, you can expect your child to have some pain. The first couple days, the site is most tender. Tylenol or Motrin usually work for most children. If your child is uncomfortable and you think they need something stronger, tell your nurse.

You may give your child pain medicine on a schedule for the first couple days. Then you can start to give the medicine less often. The pain will get better each day.

Activity

Most children are able to get out of bed, sit in a chair, or walk the day of their tube surgery. You can expect your child to be back to their usual self after about 2 weeks.

Most babies can be held the day of their tube surgery. Tummy time depends on how they handle it. This is usually about 2 weeks after the tube is placed.

Older children can be active, run around, play, swim or take part in sports with a tube.

Drainage

Some mild bleeding at the site is common in the beginning. As the site is healing it is normal to have it crust and drain. This can last several weeks.

Redness

As the skin is healing from surgery, the site can have a little bit of redness or irritation. You will learn how to care for redness at home.

Watch the videos at <https://childrenswi.org/gtube>

Tube and skin care

It helps to have a daily routine to care for your child's tube and to check the skin around the tube. Bath time is a good time to do these cares.

It is important to do good site cares and keep the tube secure while the tract is healing for the first 6 to 12 weeks.

Check and clean the skin around the tube every day, or more often if needed. Look at the site to make sure it looks healthy.

It is best to have a site that is clean and dry with a secure tube.



Cleaning the skin

Steps

1. Get your supplies.
 - Wash cloth or cotton-tipped swabs
 - Mild soap and water
2. Wash your hands with soap and water.
3. Remove any dressing.
4. Use cotton-tipped swabs or a washcloth. Wet them with soap and water to clean the skin around the tube. It is important to clean around and under the tube. Try to get all the drainage off the skin.
5. Rinse the soap off.
6. Dry the area around the tube.
7. Spin the tube in the tract every day with site cares. This stops the skin from sticking to the tube.



When not to spin the tube:

- If your child has a GJ-tube. This will cause the tube to twist which can change the position of the tube on the inside.
- If your child has stitches on the tube. Wait until the stitches are removed.

Other information

Do not use any creams or powders on the skin unless you are told to do so.

If you notice that the skin around the tube has crusty dried drainage, try this:

- Soak gauze or a washcloth with warm water. Put around tube to loosen crusty drainage. Leave on the skin for 5 to 20 minutes.
- Gently wipe to remove drainage.
- Removing the drainage will help the skin heal properly around the tube.

Bathing and swimming

Your child can shower 2 days after the tube is put in.

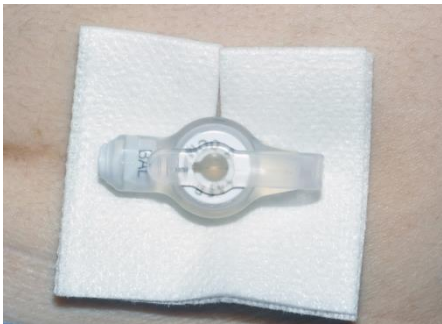
Your child can start taking baths 1 week after the tube is put in.

Your child can go swimming 1 month after the tube is put in.

Dressings

A dressing is used when there is drainage. If there is no drainage at the site, then it is best to leave the site open to air.

A 2 inch by 2 inch split gauze can be used at the site. Only use piece of split gauze at the site. You can use the pre-cut gauze if you have it or you can make your own.



Change the dressing every day when cleaning the skin. If the dressing is dirty, you may need to change the dressing more often.

I can show you how to put a dressing on the site and tell you when it's needed

Securing the tube

It is very important to keep the tube secure, especially while the site is healing. The tube should not lean or pull at the site. If you find the tube leaning or pulling often, then you may need to find a different way to secure the tube.

If your child is active, you will need to be creative and very careful to make sure the tube is secure at all times. Keeping the tube secure will help keep the tube from being accidentally pulled out. There are many ways to secure a tube.

I can show you how to secure the tube and tell you other ways too

Tension loop

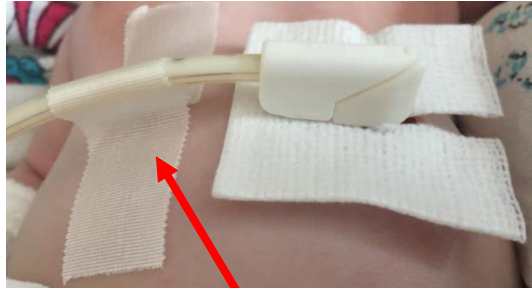
A tension loop should be used with long tubes. It should also be used if a child is vented or fed continuously. A secure tube will help keep the stoma site healthy.

A tension loop can help:

- keep the tube secure.
- stop the tube from being accidentally pulled out.
- stop the tube from wiggling at the site.

Change the tension loop if:

- the tube is leaning.
- if the tension loop fell off.
- if it has been in the same spot on the belly for 3 days.



Tension loop

How to make a tension loop

1. Get your supplies.
 - 1 x 4-inch piece of tape. It is okay to use a smaller piece of tape on a baby.
2. Put tape over tube near site.
3. Wrap tape around tube until the tape meets.
4. Pinch the tape together where it meets.
5. Put the ends of the tape and stick on the skin.

It is best to put the tension loop about an inch from the stoma site. There will be less slack and less wiggling this way.

Bolster to secure long tubes

This is used for long tubes without a bar or disc to hold it secure. Bolsters are most often used for Pezzer tubes or Foley tubes.

To learn more about bolsters

- See References: How to make a bolster
- Watch video on <https://childrenswi.org/gtube>
- Read teaching sheet on [bolsters](#). Ask your child's nurse for this or find it on <https://childrenswi.org/gtube>



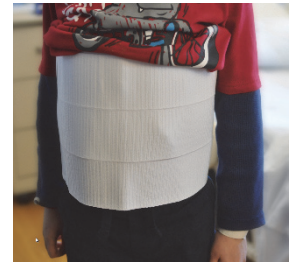
Other ways to secure all types of tubes

Ideas to protect the tube for active children.



Onesie

- Elastic binder or a belly band.
- An adult stretch headband or top.
- One-piece undershirt, sleeper or long t-shirt tucked into the pants.
- Run tubing through clothing and out the leg of the pants. This makes it harder for a child to reach.



Belly band

Key points

- Keep the site clean.
- Keep the site dry.
- Keep the tube secure.



Helps keep the site healthy

Chapter Three:

Feeding, flushing, venting and supplies

For more information on how to give feedings, see the video at <https://childrenswi.org/gtube>.

Feeding your child with a tube

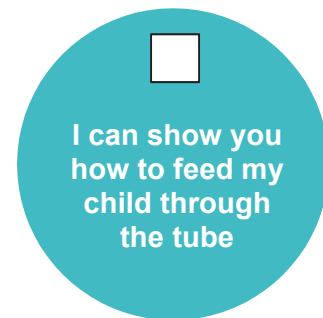
All children need food for health, energy, growth and development. Food has calories, protein, carbohydrates, fat, vitamins, minerals and water.

How much food and what kind of food your child needs will depend on:

- how old your child is.
- how fast your child is growing.
- your child's medical condition.

The best way to be sure your child is getting the right food is to keep track of your child's growth. You should also have your child's growth and feeding plan checked at regular times. This can be done by a dietitian or doctor.

A dietitian will work with you to make a feeding plan for your child before you leave the hospital.



Other thoughts

If your child cries during the feeding, the feeding will not flow smoothly into the stomach. It is best to stop the feeding, calm your child and then finish the feeding.

Formulas

There are many formulas or feeding choices for tube feeding. You and your child's health care providers will choose what is best for your child.

Examples:

- Liquid ready to feed formula.
- Powdered formula.
- Expressed breast milk.
- Blenderized food.

Formula

Store unopened formula at room temperature.

After they are opened, cover and keep open containers in refrigerator. Use within 24-48 hours.

Mix powdered formula using the recipe given by your child's dietitian or doctor. Sometimes these directions might be different than what is on the formula package.

Infants under 1 year of age

For infants under a year old, expressed breast milk or infant formulas are best. They meet a baby's needs. Other liquids, thin baby foods or liquid medicine may also be given through the tube. Only give medicines that your baby's doctor tells you to give. Your baby's doctor and dietitian will also tell you how and when to add new foods to your baby's diet.

Bonding time while tube feeding babies

Feeding time is a special time for you and your baby. If your baby did not need a tube for feeding, they would be held during the feeding. Your baby will like being held close, cuddled, rocked and talked to during their tube feedings. Turn off the TV and put your phone aside while you are feeding your baby.

Hold your baby upright while feeding them through the tube. This is safer for your baby. Burp your baby during and after feedings.

Give your baby a pacifier to suck. Sucking exercises the jaw and satisfies a baby's need to suck. This will also teach your baby the connection between sucking and a full stomach. Sometimes infants who are fed only through the tube for a long time may forget or lose the desire to eat by mouth. Using a pacifier may help prevent this.

Toddlers, older children and teens

Feeding is a social activity. If your child is not an infant, have them sit at the table with you so that they are with the rest of the family. When able, have your child help in giving feedings through their tube. This may be a good thing for siblings to do, too.

Feeding your child

Children enjoy being with family and friends at mealtime. Decide if it works best to tube feed your child during mealtimes with your family. There is no right or wrong way to plan the tube feeding. What is important is that you choose the method that works best for your child and your family. Turning the TV off is important for family mealtimes.

While feeding your child, keep them upright. This is safer for your child. If your child is laying down, you may need to lift the head of the bed.

Talk to your child when you are feeding them. Tell them what you are doing as you are setting up the food and connecting it to their tube.

Water and vitamins

Giving extra water

Your child must get enough fluid every day to prevent dehydration.

Watch for signs that your child is not getting enough fluids.

- Less amount of pee.
- Dry mouth and lips.
- Feeling dizzy.

3-4 Caring for a child with a feeding tube

Formulas are good sources of fluid, but your child may need extra water to meet daily fluid needs. Just like you will drink something along with your meal, your child will need some extra water with their formula. This is called “extra free water.” Your child’s doctor or dietitian will tell you how much extra free water your child needs. Extra water is often given after medicines, or in between or after feeds.

Vitamin and mineral supplements

Most formulas used for tube feedings have enough vitamins and minerals for infants and children. However, if you are making your own blended foods at home, extra vitamins or minerals may be needed. Your child’s doctor or dietitian will help you decide what your child needs.

Oral feeding

Parents often want to know whether a child that has tube feedings can also eat food by mouth. This is different for each child. Some children need a tube because they cannot eat enough calories by mouth to grow. Often these children can also eat by mouth.

Some children cannot eat foods safely by mouth because the food may go into their lungs (airway). This is called aspiration. Children who aspirate may not be able to eat any food by mouth. Others may only be able to eat or drink small amounts of certain kinds of foods. If your child is working with a speech therapist, they will tell you whether your child can eat safely by mouth.

Oral hygiene

Even if your child does not take any food or liquid by mouth, it is important to care for your child’s mouth. Mouth care can stop dry mouth, cavities and gum problems.

Tube feedings and schedules

There are different ways to feed your child using the tube. You and your child’s health team will decide what is best for your child. They will also help you find a feeding schedule that fits best into your family routine. This can change as your child’s needs change.

Methods of feeding

Continuous drip feeding

Feedings are given slowly throughout the day and night. It is given by a feeding pump.



EnteraLite Infinity Pump



Kangaroo Joey Pump

Feeding using a pump

A pump controls the flow of the formula from a feeding bag through the feeding tube. The pump moves the formula into the body at a set rate.

The pump can connect to a pole or fit in a backpack. Your child should be able to move around while they are being fed.

Your nurse or home care company will show you how to use the pump. You can also check the manual or go to the company's website for videos on how to use the pump.

Giving continuous or drip feedings

Steps

1. Get your supplies.
 - Formula or liquid food
 - Feeding bag
 - Feeding pump and IV pole
 - Feeding extension set if your child has a button-type of tube
 - Water for flushing
2. Wash your hands with soap and water.
3. Pour formula in the bag.
4. Prime feeding bag and tubing. This is to get the air out of the tubing.
5. Attach end of primed feeding bag tubing to the feeding tube.
6. Unclamp the tube.
7. Turn on the pump.
8. Give the amount of feeding at the rate that the doctor or dietitian told you.
9. Give extra water if you were told to do so. Sometimes you will be told to give your child extra water at the end of the feeding. Only give this if your child's doctor or dietitian told you to do so.
10. Flush the tube. Use quick, short pushes to clear the tube and extension tubing.
11. Clamp the tube.
12. Disconnect the tubing.
13. Rinse or wash supplies with warm soapy water.



Giving bolus feedings

Bolus feeding

Certain amounts of formula are fed at different times during the day or night. A large feeding syringe, a gravity drip bag or a feeding pump can be used to give this feeding for about 20 to 30 minutes. This is the amount of time that most children take to eat a meal.



Steps

1. Get your supplies.
 - Formula or liquid food
 - Feeding bag or gravity feeding system or large syringe
 - Feeding pump and IV pole
 - Feeding extension set if your child has a button-type tube
 - Water for flushing
2. Wash your hands with soap and water.
3. Give the feeding by either a feeding bag or a syringe.
4. If you are using a feeding bag, prime tubing. This helps to get the air out.
5. Attach the feeding bag or syringe (remove plunger first from syringe).
6. Unclamp the tube.
7. Pour the formula into the syringe or the bag. If using a pump, turn it on.
8. After feeding is done, give extra free water if you were told to do so.
9. Flush the tube. Use quick, short pushes to clear the tube.
10. Clamp the tube.
11. Remove the syringe or feeding bag and extension set if needed.
12. Rinse or wash supplies with warm soapy water.

A note about feeding by gravity

Formula flows down from a large syringe or feeding bag through the feeding tube. You can control how fast or slow the food goes into the stomach. Do this by raising or lowering the syringe. If using a bag, you can control by moving the roller clamp. Never plunge or push the formula. Always let the formula flow by gravity. This method is called bolus or gavage feeding.

Combination drip and bolus feeding

Some children get bolus feedings during the daytime and continuous drip at night.

Feeding through a GJ-tube

Feedings are given by a slow drip method to children with GJ-tubes. This helps keep the feedings from causing your child to vomit, have diarrhea or discomfort.

Feedings will be given directly into the jejunum which is a part of the intestines.

- Always give continuous feedings with the feeding pump through the **J-tube** or **J-port** of the **GJ-tube**.
- **Never** bolus feed into the intestines through **J-tube** or **J-port** of the **GJ-tube**.

Flushing

It is important to flush feeding tubes after each use.

Reasons for flushing:

- Flushing helps push all the food or medicine through the tube.
- It also stops the tube from clogging. Sometimes the amount of water used to flush may be smaller or larger.

If your child is on a fluid restriction, it is okay to flush with a small amount of air through the tube. Your child's doctor or nurse will tell you how to flush.

Often, the amount of water is 2 to 5 mL after feedings and medicines.

GJ-tubes

These tubes need to be flushed more often, to help prevent clogging.

- Flush the J-port with 2 to 5 mL of water every 4 hours.
- If your child has a break between feedings, flush after the feeding is done.
- It is important to flush the J-port every 4 hours, even if a feeding is still going.
- Flush the J-port after giving each medicine. Crushed pills and thick medicines can clog the tube easily. You may need to give a small flush in between each medicine.
- Flush the G-port with 2 to 5 mL of water once a day.



Venting the G-tube

Venting lets your child's stomach get rid of extra air or food. It is known as burping through the G-tube.

I can show you how to vent the tube and tell you when it's needed



When should I vent?

If your child can not tolerate a feeding they may be vomiting, gagging or retching, crying or crabby, or have swollen belly.

Venting may be needed if your child is showing signs of discomfort. You can vent:

- before feeding.
- during feeding.
- after feeding.

Steps

1. Clamp the G-tube.
2. Put a large syringe without the plunger into the port of the G-tube. Hold the syringe up and unclamp the G-tube.
3. After unclamping the G-tube you may hear air or see food or stomach juices come up in the syringe. Allow venting for 1 to 2 minutes.
4. After all food and stomach juices have gone back down the G-tube, clamp the tube and remove the syringe. Sometimes the stomach juices may not go back down. You can use the plunger to gently push the stomach juices back down.
5. Flush the tube with water if needed.

Do not throw away stomach contents unless you are told to do so.

If your child's stomach contents overflow, put the juices in another container. Re-feed the juices when your child is calm. These juices have important body salts called electrolytes. They may also have medicines that were given earlier.

If your child had a Fundoplication procedure done, the stomach may be a smaller size. Venting is often needed several times a day if your child had a Fundoplication procedure.

Supplies

Supplies for feeding are available through home supply companies, known as DME. A Case Manager will help arrange for supplies in the hospital when your child gets a feeding tube placed.



Home supply company

After your child goes home with a new feeding tube, supplies will be delivered to your home. Most insurance companies will cover basic feeding supplies.

It is helpful to keep the phone number for the home supply company. This way, when you are getting low on supplies, it is easy to call them to reorder supplies.

The home supply company can answer questions about feeding supplies and pumps.

Cleaning the supplies

It is important to keep all your supplies and equipment clean.

Rinse all supplies with water after each use.

Hand wash all supplies with hot soapy water each day.
Rinse and air dry.

If the feeding supplies become sticky or look cloudy, a 3:1 water and vinegar solution (3 parts water and 1 part white vinegar) can also be used to clean the equipment.



Clean the ports every day with water and toothbrush if they are ENFit tubes. This will get rid of the buildup of formula and help keep tubing from sticking in the port.

How often to change supplies

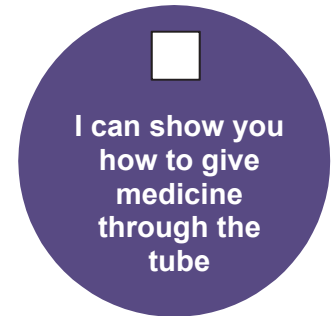
- Use a new extension set every week.
- Change the feeding bag every day. If your supply does not give you enough bags, wash them. Use dish soap or 1 cup of water to 1 half cup of vinegar. Swish around and rinse it out.

Key points

- Tube feedings are given in different ways. It is important to know which way your child can be fed.
- Sometimes children are not comfortable during a feeding. There are different reasons why this happens. Venting can help.
- Do not over twist the syringes or tubing into the ports. Stop when you meet just a little bit of pressure. Over twisting could cause the port to crack or break.
- Clean the supplies after each use.

Chapter Four:

Medicines



For more information, go to <https://childrenswi.org/gtube> for a video.

Important medicine information

- Know the names of the medicines your child is taking.
- Make sure to give all medicines as directed. Do not skip, change or give extra doses unless the doctor or nurse tells you to.
- Keep all medicines in their original container. The label shows the medicine name, dose and expiration date. It also helps keep the medicine fresh.
- Keep medicines where children cannot get at them. If a child accidentally swallows the medicine, call the Poison Control Center right away at 800-222-1222.
- Bring medicines, or a list of your child's medicines and dosages, to each clinic visit.
- Keep medicine in a dry place, away from heat or direct light. Store medicines at room temperature unless you are told to refrigerate them.
- Carry medicines with you when you travel. Do not store them in your luggage.
- If your child has any side effects from a medicine, call your doctor or nurse.
- If your child misses a dose or throws up a dose, call your doctor or nurse. Do not skip or give an extra dose unless the doctor or nurse tells you to.

Giving medicine



It is best to give liquid medicine through the tube. If your child's medicine comes as a pill, ask your child's doctor or pharmacist if it can be crushed. Some medicines cannot be crushed. If allowed, crush it into fine powder and mix with tap water.

Check with your child's doctor, nurse or pharmacist to see if the medicine your child takes should be given before the feeding or with the feeding.

Syringes are usually not covered by insurance. It is best to reuse medicine syringes as long as they are being rinsed in between use and you can still read the markings.



How to give medicine through a tube

Some tubes have a medicine port. One port can be used to give medicine while the other is used to give feedings.

If your child has a GJ-tube or J-tube, ask your child's doctor if the medicine should be given into the G-port or the J-port.

You can push medicine through the tube by putting the medicine syringe into the port of tube or extension set.

You can also give medicine into a large syringe attached to the tube and let it go down through the tube by gravity.



Steps

1. Get your supplies.
 - Syringes
 - Extension set if needed
 - Medicines (have them drawn up and ready to go)
 - 2 to 5 mL of water for flushing, before and after each medicine
2. Wash your hands.
3. Clamp the tube.
4. Insert the syringe of water into the port.
5. Unclamp the tube.
6. Flush the tube with water.
7. Clamp the tube.
8. Insert the syringe with the medicine into the port.
9. Unclamp the tube.
10. Push the medicine into the tube.
11. Clamp the tube. This will help the medicine from coming back out.
12. Insert the syringe of water into the port. This makes sure all the medicine is out of the tube and into your child.
13. Clamp the tube.
14. Remove the syringe from the port.
15. Close the cover on the port and remove any extension sets.

Key points

- Medicine can be given in different ways. Liquid medicine is easier to get through the tube.
- Ask your child's nurse, doctor or pharmacist how to give the medicine.
- Give your child the full dose.
 - Clamp the tubing in between each step so that the medicine does not come back out.
 - Contact your child's doctor or nurse if your child does not get their full dose.

Chapter Five:

Preparing for home

When and how to call the team managing your child's feeding tube

Your After Visit Summary (AVS) will tell you when and how to contact the nurse or health care provider.

Care team members

Remember, you are an important member of your child's team. Be ready to tell the team about how your child has been doing.

Clinic assistant

- Measures your child's height and weight.
- Checks blood pressure, heart rate, breathing rate and temperature, if needed.

Nurse Clinician

- Reviews and update your child's medical history since the last visit.
- Reviews your child's medicines and prescriptions.
- Reviews your child's daily schedule.
- Discusses activity and therapy.
- Answers questions and discuss concerns.
- Helps order supplies needed for home.

Dietitian

- Reviews your child's growth and diet.
- Makes suggestions for changes to the feeding plan, if needed.

Health Care Provider

They will examine your child and talk about your child's plan of care. This includes:

- Doctor.
- Physician assistant.
- Nurse practitioner.
- Fellow.
- Resident or intern.



Contacting your care team

There are a couple ways to contact your child's care team members.

Phone

Keep a complete list of all phone numbers you may need before you leave the hospital. You may want to add these numbers to your cell phone.

- Number to call for doctor or nurse:
 - during regular business hours.
 - when you have an urgent concern.
- To make or change an appointment: Central Scheduling (414) 607-5280.
- Home supply company also called DME (Durable Medical Equipment).
- Pharmacy.

MyChart

One of the best ways to contact your child's care team for **non-urgent** concerns is through MyChart. You can:

- send emails and pictures.
- check lab results.
- make appointments.
- ask questions.

It can take 24 to 48 hours to get a response.

Use the app to help keep track of your child's information. You can download it at:

<https://chw.org/patients-and-families/mychart>.

Clinic visits

After going home, your child will need to come back to the gastroenterology (GI) or Surgery clinic for follow-up visits.

What to expect at your child's regular clinic visits. We will:


- review your child's health and plan for care.
- check the fit of the tube as your child grows.
- review medicines and dosages.
- do lab tests or x-rays, if needed.
- check for any problems.
- teach you new things you need to know.

Items to bring to clinic

- A list of your child's medicines.
- Supplies your child may need while you are in the clinic or at the hospital:
 - Extension set.
 - Syringe.
 - Feeding supplies.
 - Water, formula, or medicines.
 - Spare dressing or gauze.
- Write down your questions and concerns. This will help you to remember so you can discuss them with your care team.

First tube change

After your child's tube is placed, it will need to be changed in the clinic for the first time. This usually happens 6 to 12 weeks after the tube is put in. It is important that the tube does not get changed until the tract is fully healed.



I can tell you about when my child will have their first tube change

If the tube falls out before the first tube change, cover the stoma with gauze or a washcloth and take your child to the Emergency Room. Do **not** try to put the tube back into the stoma unless your child's nurse or doctor tells you to do this. You will not have a spare tube at home until after the first tube change.

Sometimes your child may need medicine to go to sleep when they have their tube changed. Your child's doctor or nurse will tell you if this needs to happen.

For a video on how to change a tube, visit: <https://childrenswi.org/gtube>

Once the first scheduled tube change is done, you can change the tube at home. We will teach you how to change the tube when you come to the clinic.

Common problems

It is normal to have the site crust and drain while the tract is healing. It is also common to see a small amount of redness which may come and go. Sometimes when your child gets sick, their tube site can look sick. This includes:

- A small amount of redness.
- Extra drainage.

5-4 Caring for a child with a feeding tube

Follow these steps to help keep problems from happening

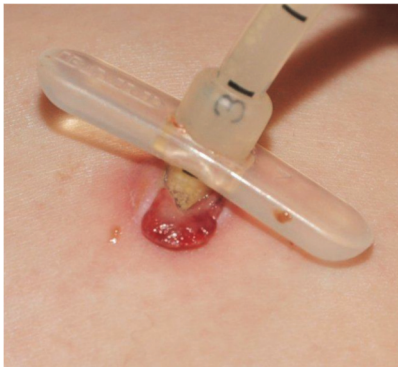
- Keep the site clean and dry.
- Keep tube secure.
- Flush the tube when needed.

How to deal with tube and skin concerns

Problems can happen with even the best of care. Call your child's doctor or nurse if the tips below do not help.

Granulation tissue

Granulation tissue is extra growth of healing skin. This is a normal response of the body. It is very common. It does not mean there is an infection. It is pink or red, moist tissue that is seen where the tube comes out of the skin. This tissue is like the tissue inside the cheek. It may cause a yellow-green thick sticky



drainage or small amount of bleeding. Most often, it is not painful.

Talk to your child's nurse or doctor if you think you see granulation tissue. It is not an emergency, but you should make them aware of it if you do not know what to do.

I can tell you
what to do if
there is
granulation
tissue

Ways to prevent granulation tissue

- Secure the tube. See Chapter 2.
- Keep site clean and dry.
- Have your child's nurse or doctor make sure the fit of the tube is good.

Treatment for granulation tissue

A steroid cream for skin is often prescribed by the doctor. If the stoma site is newer than 30 days, other treatments may be advised.

If the tissue has grown very big or causes other problems, the tissue may be removed with silver nitrate in Clinic.

How to use steroid cream

- Use a cotton-tipped swab to put a thin layer of cream only on the raised granulation tissue.
- Apply the cream 2 to 3 times each day until there is no more raised tissue.
- Do not treat with the steroid cream longer than two weeks. After that, if it is not better, call the nurse or doctor.
- If there is still some tissue after not treating for one week, you might need another treatment of the cream. You can apply the cream for another two weeks.

Silver nitrate sticks

This is most often done in the clinic. The nurse will use the sticks to shrink the tissue.

Sometimes the medicine gets onto the skin near the tube. This may stain the skin a dark color. The stain will go away after a few days. Follow the directions the nurse give you after silver nitrate is used on the tissue. If you notice blisters or peeling skin, call your nurse or doctor.

Emergencies

Things that need medical attention right away

With any of these concerns, stop the feeding. **Take your child to the Emergency Room.**

- **Small bowel obstruction**

Signs of this may include:

- green fluid coming up into your child's tube or throwing up out of mouth.
- swelling or pain in the belly.
- a change in your child's normal activity. Child seems weak or more tired.

- **Tube not in the right place**

Sometimes when you change the tube, it can go in the wrong place. Signs include:

- Runny poop.
- Gagging or throwing up.
- Belly pain.
- Change in normal activity.
- Weakness or more tired.
- Fever.


These signs most often happen during or after feedings after the tube has been changed.

- **Large amount of bright red blood in the tube.**

Guide to concerns

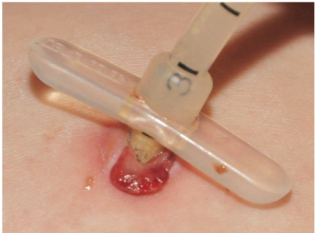
Problem	Reasons	What to do
Throwing up, cramping or bloating	The feeding rate is too fast or this is too much food in the stomach.	Slow the rate or try less food. If this does not work, try holding the feeding for an hour and then give it slowly. If it keeps happening, talk to the dietitian about changing the speed of the flow.
	Your child has a virus or too much air in the stomach.	Vent the stomach. See Chapter 3 on how to do this.
	The tube may not be in the right spot.	Contact your child's doctor if the throwing up has not stopped. If your child is very sick, call right away. They may be very tired and have a fever if they are very sick.
	Formula is too cold.	Make sure the formula is at room temperature before using.
	Change in formula.	Contact your child's dietitian if your child's formula changed recently.



5-8 Caring for a child with a feeding tube

Problem	Reasons	What to do
<p>Runny Poop This is when there is more than 3 loose or watery poops a day. This is called diarrhea.</p>	<p>Feeding rate is too fast.</p> <p>Your child has a virus.</p> <p>Change in formula.</p>	<p>Slow the rate or try less food. If this does not work, try holding the feeding for an hour and then give it slowly. If it keeps happening, talk to the dietitian about changing the speed of the flow.</p> <p>Contact your doctor if the pooping does not stop.</p> <p>Contact your child’s dietitian if their formula has recently changed.</p>
<p>Skin site red because of drainage</p> <p>A little redness can be normal.</p>	<p>It may be from damp skin because of the drainage.</p>	<p>Clean the skin site more often with mild soap and water. Keep the site dry.</p> <p>Put on a dry dressing if there is drainage.</p> <p>Diaper rash creams, like those made with zinc oxide may be used around the tube.</p> <p>Contact your child’s doctor or nurse if the skin does not get better.</p>
<p>Skin site is red and itchy with tiny red bumps (rash)</p> 	<p>This is often because of damp skin from drainage.</p>	<p>Be sure skin is dry. If the rash does not go away, contact your child’s doctor or nurse. A special medicine may be needed.</p>

I can tell you what to do if the site is red

Problem	Reasons	What to do
Coughing, choking or trouble breathing during or right after a feeding	Formula may be coming back up from the stomach into the throat.	Slow down the rate of the feeding. If the problem continues, contact your child's doctor or nurse.
Leaking at the skin site	If the tube has a balloon, water could be leaking from the balloon. If the tube has a bumper, it may have slipped away from the stomach wall. The size of the stoma is larger than the tube.	If you have been taught , check the amount of water in the balloon. Add more water, if needed. Gently pull back on the tube to be sure that the bumper is snug against the stomach wall. See Chapter 2 for more information. Secure the tube to help keep it from wiggling. Contact your child's doctor or nurse if the skin is red, peeling, or you have other concerns about the size of the stoma.
Feeding does not run through the tube	Tube is clamped. Blockage due to food or medicine	Unclamp the tube. Follow these steps 1. Start at the top of the tube and squeeze by rolling the tube between your fingers to dislodge the blockage. 2. Flush the tube with warm water using a push pull method. Take the plunger and push and pull it back and forth.

Problem	Reasons	What to do
<p>Feeding does not run through the tube</p>		<p>Note: Do not use juice or soda to unclog the tube. This will lead to more clogging later.</p> <p>If your child has a button type tube, there may be a clog in the extension set. Disconnect the extension set and flush it out over the sink.</p> <p>How to keep the tube from clogging</p> <ul style="list-style-type: none"> - After each feeding or medicine dose, always flush with 2-5 mL of water before clamping the tube. - Only use liquid medicine. If your pharmacist tells you, crush pills well and mix in water. - If formula seems too thick, thin it. Talk to the dietitian to find out how to do it. <p>Contact your child’s doctor or nurse if you are not able to unclog the tube.</p>
<p>Extra tissue growth This could be granulation tissue.</p> 	<p>Moisture at site, unstable tube, tube that does not fit well.</p>	<p>This is common. It does not mean there is an infection.</p> <p>See Chapter 2 on how to keep tube clean and secure.</p> <p>Contact your child’s doctor or nurse to have this treated.</p> <p>See Granulation tissue section in this chapter.</p>

Problem	Reasons	What to do
<p>Bleeding around the tube or stoma</p>	<p>Tube leaning or pulling.</p> <p>You may see bloody drainage if there is granulation tissue.</p> <p>Bleeding may happen after a tube change.</p>	<p>Secure the tube. See Chapter 2 on how to secure the tube.</p> <p>Look to see if there is granulation tissue. Contact your child's doctor or nurse if you see this tissue. If your child has been treated for this tissue and you still have medicine, you only need to let the doctor or nurse know if the medicine is not working.</p> <p>Do not be alarmed at a little bleeding. Contact your child's doctor or nurse if the bleeding does not stop.</p>
<p>Infected site</p> 	<p>Infection can be caused by many things.</p>	<p>Contact your child's doctor or nurse if you see these signs:</p> <ul style="list-style-type: none"> - Large amount of redness that is spreading. - Fever. - Swelling. - Thick and creamy drainage that is not formula. - Drainage with odor - Skin feels hard and warm.
<p>Broken parts on tube</p>  <p>Broken parts on the tube</p>	<p>Normal wear and tear or defect in tube.</p> <p>Examples include defective tube or broken port adapter.</p> <p>Normal wear and tear or defect in tube.</p>	<p>Contact your child's nurse or home supply company.</p> <p>If the port is broken on an extension set, change the extension set.</p> <p>If the adapter is broken, change the adapter if you were given a spare one.</p> <p>You can watch the video on how to change the adapter at https://childrenswi.org/gtube.</p>

5-12 Caring for a child with a feeding tube

Problem	Reasons	What to do
	Examples include defective tube or broken port adapter.	If you don't have a spare adapter, contact your child's nurse.
Feeding pump not working	There are many reasons a feeding pump may not work.	Check the manual or contact the home care supply company. Sometimes the pump manuals can be found online. If you are unable to fix the feeding pump, you could try feeding through a syringe. See Chapter 3.
Tube or button comes out	<p>The tube has been pulled out.</p> <p>The balloon is broken or does not have enough water.</p>	<p>Try to stay calm. This is not an emergency. The tube needs to be put back in within 1 to 2 hours.</p> <ul style="list-style-type: none"> - Put a washcloth or gauze over the opening. - If the tube has never been changed, do not put anything into the tract. Bring your child to the Emergency Room. <p>If you have been taught to change the tube, then replace the tube.</p> <ul style="list-style-type: none"> - If the tube that came out is broken or dirty, use the spare tube. - If the tube that came out is not broken, and it is not dirty, you can put it back in.

Chapter Six:

Resources

Parent to parent

General advice

Relax, and don't give up. Ask other parents.

Join social media groups, or follow parent blogs for children who have feeding tubes.

Use a baby monitor to listen for your child.

Feeding

“As a nurse, I always warned parents that stomach contents might come out the tube, especially during bolus feedings.”

Be prepared. If you are feeding or venting with a syringe or if your child is crying or coughing, tummy juice and formula will come back up into the syringe. The juices may look curdled. Don't worry. This is normal. It does not mean that anything is wrong. Just calm your child and re-feed. It can be hard if your child won't calm down.

Sometimes it is hard to work around your child's feeding plan. This is especially true when other children need to be taken to and from school or when you need to go to a doctor's appointment. It is okay to give the feeding for a shorter time or change the feeding plan for the day. If this happens a lot, talk to your dietitian about changing the plan.

Talk to the nurse or dietitian about how to understand your child's hunger signals, if they can eat some things by mouth.

“I found a device that makes it easier to open formula cans. It was in the soup aisle, and is intended for opening cans that have pull-tabs. I tried it and it worked like a charm. No more sore thumbs!”

6-2 Caring for a child with a feeding tube

Feeding pumps

“I love the small pump. Since my child is on continuous feeds, the pump’s small size is ideal for me. We can go about our day while they eat.”

For kids who need feeding pumps, there are several different kinds. Many times, you will get the pump that your equipment company uses the most. If you have problems with it, like lots of beeping, call the home care or clinic nurse for help. You may not have to stay with the same brand of pump or even the same home care supply company.

Before making changes, always check with your insurance company.

Here’s a link to an interactive site that walks you through using the Kangaroo pump:

<https://www.cardinalhealth.com/prtraining/kangaroopumptraining/covidien.html>

Extension sets

Don’t over-twist the extension set when connecting it to the button.

Keep tubing from getting wrapped around an active child.

- Tuck the tubing under clothes. Use a onesie, t-shirt, or other belly band.
- Run tubing through clothes and out the leg. It’s harder for the child to reach, and the tubing moves with the child.

Tips for cleaning the extension set:

- After rinsing, run the partly closed clamp up and down the tube. Then rinse again. You can also roll the tube between your fingers to loosen the formula stuck in the tube. Start with cold water so that the formula does not stick as much.
- Your home care company may have a long, thin brush that you can order to help with cleaning the tube.

Changing the tube

If your child has already had their first tube change at the clinic, you can carry an emergency kit. The emergency kit will be helpful if your child’s tube comes out when you may least expect it.

The kit should have a spare tube, sterile water, a syringe for the balloon and some lubricating gel. Keep an extra syringe, gauze, water and hand sanitizer in your kit.

Traveling

Take all your child's supplies with you. It is helpful to have extra supplies just in case you need them.

- If you are flying, put all supplies in your carry-on luggage.
- You can use a lamp pole to hang the feeding bag.
- Check with your insurance company on coverage for health care when you leave town.
- Ask your home care supplier if they can ship formula to where you are going.

Family support

There are many organizations that may help you. See below.

Daniel M. Soref Family Resource Center at Children's Wisconsin

May also help network you with other families who have feeding tubes.

(414) 266-3169

<https://childrenswi.org/patients-and-families/milwaukee-campus/inpatient-visit/during-your-stay/family-resource-center>

Parent to Parent of Wisconsin

Parent to Parent of Wisconsin offers parent support to parents of children with special needs. Matches are made with trained parents who know about the feelings and realities that come with having a child with special needs.

(888) 266-0028

<https://www.p2pwi.org/>

The Children and Youth with Special Health Care Needs Program

This program can help you by suggesting resources you may not know about. They may also have videos and books about tube feeding and oral eating problems. These regional centers are helpful with consulting, referrals and follow up services.

- At Children's Wisconsin, Milwaukee:
(800) 234-5437
www.southeastregionalcenter.org
- At Children's Wisconsin, Fox Valley:
(877) 568-5205
<https://www.northeastregionalcenter.org>

Financial

If you need help for medical expenses, talk to your social worker or someone in the Children and Youth with Special Health Care Needs Program. They can help you learn how to get help to pay for what your child needs. Ask about some of these resources:

Supplemental Security Income (SSI) – This program offers an insurance card and a monthly payment. Families who have a low income may be able to get it. Apply through your local Social Security Office or by calling.

(800) 772-1213

<https://www.ssa.gov/ssi>

Badger Care Plus

Badger Care is a program that provides insurance for families in Wisconsin who do not have it. Learn more at: <https://www.dhs.wisconsin.gov/badgercareplus/index.htm>

Medical Assistance Spend Down – Local County Health and Human Services Offices can help you to look at your medical costs and how it affects income. This may help your child get Badger Care Plus.

Katie Beckett Program – This program is for children with long-term disabilities or complex medical needs and who are living at home. They help families get an insurance card. Parent income does not matter. To learn more, visit:

<https://www.dhs.wisconsin.gov/kbp/index.htm>

Children’s Community Options Program (CCOP) – These funds are for getting the things that are listed in the child and family-centered individual service plan (ISP). Your county will help develop the ISP if your child qualifies for this program.

<https://www.dhs.wisconsin.gov/ccop/family.htm>

Children’s Long Term Support Program (CLTS) – This program uses Medicaid funds for children who have major challenges and need support to stay in their home or community. <https://www.dhs.wisconsin.gov/clts/waiver/family/index.htm>

For more information or to apply for Katie Beckett, Medicaid, Children’s Community Options, or Children’s Long Term Support programs visit <http://www.compasswisconsin.org/>. You can get help from Compass Wisconsin if you live in these counties:

Adams	Columbia	Dane
Green	Jackson	Jefferson
Kenosha	La Crosse	Lafayette
Marquette	Monroe	Ozaukee
Racine	Rock	Walworth
Washington	Waukesha	

Families in other counties should contact their county’s social or human services agency: <https://www.dhs.wisconsin.gov/clts/contact.htm>

Nutrition resources

Insurance may or may not pay for formula. Start with the resources below to get help.

- Your insurance company – call to see if formula is covered.
- The formula company – some formula companies have programs to help you with formula when insurance denies it.
- WIC – you may be able to get help from WIC. It may include formula benefits.

Women, Infants and Children (WIC) Program – This is a special nutrition program. It is meant to get good food to pregnant, breastfeeding, postpartum women and their kids. Learn more at: www.fns.usda.gov/wic

Katy’s Kloset – this program lends medical equipment for free. They often have tube feeding supplies and formula that have been donated by those who no longer need it. Katy’s Kloset is a service of Team Up! With Families: <http://www.teamupwithfamilies.org/katys-kloset/>

School and therapy

Birth to Three Program – This is a program for infants and toddlers who may have a delay. For more information, go to <https://www.dhs.wisconsin.gov/birthto3/index.htm>

Individual Educational Plan (IEP) – Local school districts will write an IEP for children have delays. Ask your neighborhood school’s principal to tell you about this.

CHW Schoolroom – If your child is admitted to Children’s Hospital of Wisconsin, school is offered in the classroom or at the bedside.

A social worker – After your child gets their feeding tube, a social worker can help your school get ready to care for your child at school. Ask your nurse to speak to a social worker.

Transportation

Transportation or mileage reimbursement – You may be able to get money to help pay for driving your child to medical appointments. If you do not have a car, you can get help with a ride to appointments. Your social worker at the clinic or hospital can help you with this.

Disabled Parking Permit – The Disabled Parking Identification Card can help parents of a child with a disability. To get a card fill out a form and have your doctor sign it. You can get a form at: <https://www.dmv.org/wi-wisconsin/disabled-drivers.php>

Internet resources

Families often use internet to find help. Below are some trusted resources to help support you.

Children's Wisconsin G-tube Resource page with videos.	https://childrenswi.org/gtube
Mealtime Notions, LLC - resources like helpful parent stories and mealtime tips to help you with feeding challenges.	www.mealtime notions.com
Tube Feeding Awareness - supports parents of children who are tube-fed, while raising positive awareness of tube feeding as a lifesaving medical intervention.	https://www.feedingtubeawareness.org
Wisconsin Family Voices - information and advocacy for families who have children with special needs.	https://familyvoiceswi.org
The Association of Congenital Diaphragmatic Hernia - Research, Advocacy and Support.	http://www.cherubs-cdh.org/
The National Institute of Diabetes and Digestive and Kidney Diseases - information on many digestive problems	www.niddk.nih.gov
The Child Neurology Foundation - education and support for caregivers and their children with neurologic conditions.	https://www.childneurologyfoundation.org/patients-or-caregivers/
The Society for Inherited Metabolic Disorders - Resource list for different conditions.	https://www.simd.org/Links/index.asp
MitoAction - Community of support for children and families living with mitochondrial disease.	http://www.mitoaction.org/
Short Bowel Foundation - Support and information	http://shortbowelfoundation.org
International Foundation for Gastrointestinal disorders - Support and information on GI and motility disorders.	https://www.iffgd.org/
Complex Child - website, magazine and Facebook page for families who have children with special health care needs.	https://complexchild.org/

These web sites are meant to help you care for your child. They do not take the place of medical care.

Talk with your healthcare provider for diagnosis, treatment, and follow-up.

Websites were checked when this Care Notebook was published in 2020, but may change.

Chapter Seven:

References

GJ-tube plan of care

Care of the GJ-tube

In the other chapters in this notebook, there are important things about GJ-tubes. Please review this in detail if needed. Below are the important things to remember when taking care of the GJ-tube.

Reminders on care of the GJ-tube:

- Do not spin the tube.
- Know which port is used for stomach (G) and which is used for the jejunum (J).
- Feedings into the jejunum should be given slowly using a feeding pump.
- Know which port should be used to give your child's medicines.
- Flush the GJ-tube often. Use 2 to 5 mL's of water every 4 hours.
- Know if the G-port will be clamped or vented or drained to a bag.
- GJ-tubes should be replaced in Interventional Radiology every 3 to 4 months.

What problems can happen with a GJ-tube?

- The tubing might clog.
- The tubing in the J-port might move out of place.
- The whole GJ-tube might fall out.

7-2 Caring for a child with a feeding tube

What do I do if these problems happen?

It may seem scary, but it is not an emergency if the GJ-tube has a problem. Do not come to the Emergency Room unless needed. It is best to call Interventional Radiology first. If you come to the Emergency Room in the evening or overnight, your child's GJ-tube will not be replaced until the next day.

- Some children can handle slow feedings or Pedialyte in their stomach.
- Some children may not handle anything in their stomach but can wait to have the GJ-tube exchanged.
- Most children can go without feedings or liquids for 12 hours without any harm.
- Some children may need IV fluids.
- Your child may need to be admitted to the hospital while the GJ-tube is not working. It will depend on your child's age and special medical needs. Your child's doctor or nurse should talk to you about your child's emergent feeding plan.

Who do I call if these problems happen?

It is best to call Interventional Radiology (IR) if you do not know what to do.

If any problems happen that would need your child's GJ-tube exchanged, call one of the numbers below. If the problem happens during regular scheduling hours, call right away. If the problem happens after hours or on weekends, call IR the next morning to have GJ-tube exchanged.

Day	Time	Interventional Radiology Phone Number
Monday through Friday	Scheduling hours 8:00 AM - 4:00 PM	(414) 266-3152
Weekdays after hours and weekends	After 4:00 PM	(414) 266-3116

What if the GJ-tube is clogged?

Try flushing the port with warm water or fizzy or seltzer water. Use a 3 mL syringe and push and pull on the plunger to help unclog the tubing. It is helpful to let the water sit in the tube for 20 minutes and to try again. Do not use soda or juices to unclog the tube.

If the J-port still will not flush after trying these things, contact your child's doctor or Interventional Radiology. Some children may be able to handle food through their G-port into the stomach.

What if the GJ-tube is not in the right place?

Sometimes the tubing of the J-port becomes loose and starts to get pulled out. Sometimes the tubing of the J-port may twist and move into the stomach rather than the intestines. If this happens, you may see:

- Discomfort during feedings
- Throwing up formula
- Formula from the G-port

If you see any of these problems, contact your child's doctor or Interventional Radiology.

What do I do if the GJ-tube falls out?

If this is your child's very first tube and it has never been changed before, do not try to place anything into the tract. Cover the stoma. Call Interventional Radiology if this happens during the weekday. If this happens on weekends or evenings, bring your child to the Emergency Room.

If your child's GJ tube falls out of the tract and you have a spare G-tube, you may replace if you were told to do so. If you placed the G-tube successfully and if you were told that your child may handle slow feedings or Pedialyte in the stomach, you could try this. If you don't have a spare G-tube, you could try to put the tip of the GJ-tube into the tract 2 inches and tape into place. This will keep the tract from closing.

If you are not able to put anything into the tract, contact Interventional Radiology or your child's doctor for more instructions.

Bolster dressing

This is used for long tubes without a bar or disc to hold it secure. Bolsters help keep the tube propped straight up. This helps the stoma heal correctly.

Bolsters are most often used for Pezzer tubes or catheter type of tubes.

To learn more about bolsters:

- Watch video on <https://childrenswi.org/gtube>
- Read teaching sheet on bolsters. Ask your child's nurse for this or find it on <https://childrenswi.org/gtube>



7-4 Caring for a child with a feeding tube

You do not have to remove the bolster to clean the site. If you are changing the bolster, then it would be best to clean the site at this time.

Change a bolster:

- when it is dirty.
- if the tube is not secure.
- if it has been in the same spot on the belly for 3 days.

How to make a bolster

Steps

1. Get supplies ready:
 - Gauze that is 3 inches by 3 inches
 - Half inch wide tape (4 pieces that are about 3 to 4 inches long)
2. Wash your hands with soap and water.
3. Make bolster. You can make several of them up ahead to save time. Put them in a plastic baggie.
 - Stack 2 pieces of gauze and fold in thirds.
 - Roll it tightly and tape it so it won't unroll.
4. Take off the old bolster dressing.
5. Clean the skin site if needed.
6. Gently spin the tube in the tract. This helps the stop the tube from sticking to the skin.
7. Gently pull back on the tube until the mushroom or water balloon is snug against the stomach wall.
8. Put the bolster on the skin next to the tube. Do not put bolster in the same spot on the belly.
9. While holding the tube straight up, lay the tube over the bolster and begin to secure.
 - Put 3 pieces of tape over the tube and bolster dressing. Lay them in the same direction overlapping each piece a little bit. The tape should not criss cross.
10. Put one extra strip about 1 to 2 inches away from the bolster. This is called a tension loop.
 - Fold it around until the tape meets.
 - Put the ends of the tape onto the skin.
 - This strip adds security to the tube and bolster.



Glossary

A

Aspiration - Breathing or inhaling food into the lungs or airway. This could lead to pneumonia.

B

Bolus tube feeding - Feeding a set amount at different times during the day. Feedings may be done in one or more ways. These may include syringe, gravity feeding or pump feedings.

Button gastrostomy - A short, skin level gastrostomy tube. (Chapter 1-6)

C

Cap - A cover that connects to the port of the feeding tube. This stops the stomach contents from leaking out. (Chapter 1-6)

Clamp - A device on the tube that pinches the tubing closed. This stops the stomach contents from leaking out.

Continuous drip feeding - Feeding given on a pump at a constant rate for a certain amount of time. (Chapter 3-5)

D

Dehydration - Can happen when the body does not get enough fluids. This could include less amount of pee, dry mouth and lips, or feeling dizzy.

Diarrhea - 3 or more loose or watery poops a day.

Dietitian - A person who is trained to create a feeding plan.

Dysphagia - Having a hard time swallowing.

E

Electrolyte - a nutrient that helps keep the body working.

Esophagus - The path for food to get from the mouth to the stomach. It is often called the swallowing tube.

Extension set - Tubing that connects to button tubes. It is used to give feedings and medicines.

External fixation device - A device on the tube that rests on the skin. It may look different depending on the type of tube. This helps keep the tube from wiggling and pulling.

F

Feeding Pump - A machine that feeds the formula to your child over a period of time.

Flush - An amount of water that is given to clear the tube of feedings or medicines. The amount depends on your child's needs and size.

Fundoplication (Nissen or Toupet) - Surgery that is done to treat gastroesophageal reflux. The top part of the stomach is wrapped around the lower part of the esophagus to create an internal valve. This valve will keep the stomach contents from going up into the esophagus.

G

G-tube resource nurse clinician - A nurse who is trained to care for the needs of children with G-tubes.

Gastroenterologist - A doctor who cares for people who have digestive or eating problems.

Gastroesophageal Reflux Disease (GERD) - When stomach contents back up into the esophagus. This could cause pain, ulcers, vomiting, and aspiration.

Gastrojejunal feeding tube (GJ-tube) - A feeding tube that goes through the stomach and ends in the small intestine called the jejunum.

Gastrostomy tube (G-tube) - A tube that passes through the skin into the stomach. This tube may be used for feeding or venting the stomach.

Gauze - A bandage that protects the skin from drainage.

Granulation tissue- Extra growth of healing skin tissue. It is normally seen at the site where the tube comes out of the skin. It is pink, moist tissue. You may see thick, sticky, yellow and green drainage.

Gravity drip feeding - A way of feeding only used for bolus feeding. The formula is poured into a feeding bag and the bag which is connected to the G-tube. The flow of the feeding is controlled with a roller clamp.

J

Jejunostomy tube (J-tube) - A jejunostomy tube is put directly into the small intestine. (Chapter 1-4)

Jejunum - Part of the small intestines. (Chapter 1-4)

N

Nutrients - Parts of food that nourish the body. This includes protein, carbohydrate, fat, vitamin, mineral and water.

P

PEG tube (Percutaneous-placed Endoscopic G-tube) - One way of placing a G-tube. (Chapter 1-5)

R

Radiologist - A doctor who reads x-rays and images.

S

Site - The skin around where the tube is placed. (Chapter 1-4)

Small intestines - Part of the digestive tract between the stomach and the large intestines. (Chapter 1-4)

Stoma - The opening around the tube. (Chapter 1-4)

Stoma site - The opening and skin around the tube. (Chapter 1-4)

Stomach - This holds food during the early part of digestion. (Chapter 1-4)

Surgeon - A doctor who does surgery to put in the feeding tube.

Syringe - A plastic tube with a plunger. It is used to collect or push fluid into a feeding tube.

T

Tract - The tunnel opening from the skin into the stomach. (Chapter 1-4)

U

Units of measure

mL = milliliter

30 mL = 1 ounce (oz)

V

Venting - A way to get extra air out of the stomach. This is another way to burp.

W

WIC (Women Infant Children) - This is a program for Women, Infants, and Children (WIC). It offers food, health care referrals, and nutrition education. It is for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women. It is also for infants and children up to age five who need help with getting food.