

# When Your Child Has a Feeding Tube

Your guide to care for your child



# **Contents**

Lesson 1: Your child's feeding tube	2
Lesson 2: How to take care of their skin	6
Lesson 3: How to feed your child	9
Keep your child safe	14
Words to know	15

# Lesson 1: Your child's feeding tube

# Your goals for this lesson

### You'll learn:

- why your child has a feeding tube and how it will help them
- what type of feeding tube your child has
- when and how to ask for help
- words you need to know (see page 15).

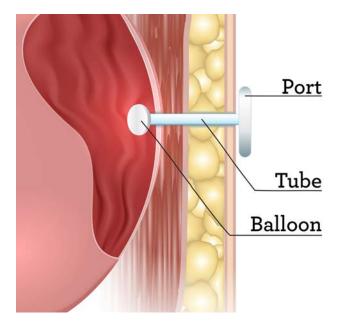
We'll go over everything you need to know. Then you'll show us what you learned at your child's bedside.

# What's a feeding tube?

A feeding tube is a special tube that lets liquids (food and medicine) go straight into the stomach or intestine.

A feeding tube has 3 main parts.

- Port (button): the part at the end of the tube that stays outside the body. It's the part of the tube you'll see. It will have 1 or more openings.
- **Tube:** the part that runs from the outside of the body into the stomach or intestine.
- Balloon: the part at the end of the feeding tube that goes inside the body. It sits inside the stomach. Once inside, we'll fill the balloon with water to hold the tube in place.



# Why your child needs a feeding tube

Your child needs to use a feeding tube because they can't eat or drink safely by mouth. Or because they cannot get enough nutrition by mouth.

The feeding tube is a safe way to give your child the nutrients and medicine they need.

And it's a way that will let their body process and use what you give them. This can help them get what they need to grow and be healthy.

# How their feeding tube was put in

During their surgery, your child's surgeon made a cut in their belly and into the stomach. Then they put the tube through that hole. To help the tube stay in place while it heals, the surgeon used stitches or T-fasteners.

- If your child got stitches that do not dissolve on their own, their provider will take them out in 7 to 14 days after surgery, or before they go home.
- If your child got T-fasteners, they may fall off on their own. That's OK. They're made to fall off. If they don't come off on their own, your child's provider will take them out in 7 to 14 days.



T-fasteners are the white circles around the port.

### Your child's body will create a stoma

A stoma is an opening in the body. After your child has their tube for about 3 months, tissue will form around it to make a tunnel. The tunnel will create a path from their stomach to the outside of their belly.

### At their 3-month visit

About 3 months after their surgery, your child will have a follow-up visit. During that visit, their provider will change the tube. After that, you can change the tube at home. About every 3 months you'll change the tube or bring them in so we can change it.

# If the tube comes out before the 1st tube change

- 1. Do not put anything in the hole.
- 2. Cover the hole with gauze or cloth.
- 3. Take your child to have the tube put back in right away and call the surgery clinic at (615) 936-1050. It's best if the tube can be put back in within 1 hour.
  - Take them to the surgery clinic if the tube comes out during regular clinic hours (Monday to Friday, 8:00 a.m. to 5:00 p.m.).
  - Take them to the closest ER if the tube comes out when the surgery clinic is closed.
  - Tell your child's nurse if the tube comes out when they're in the hospital.

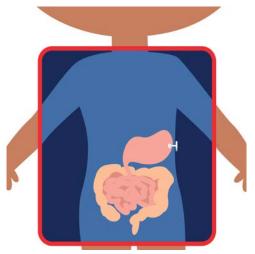
# What type of feeding tube does my child have?

There are 2 main types of feeding tubes: G-tube and GJ-tube. Both have a port that you'll see on the outside. The difference is where the liquid comes out of the tube once it's inside the body.



# G-tube (gastrostomy tube)

The tube goes into the stomach. The liquid (food and medicine) will be digested in the stomach.

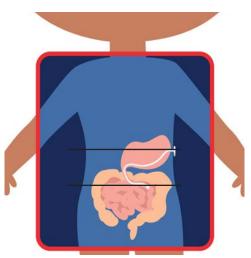


The G-tube lets liquid go straight into the stomach.

# GJ-tube (gastrojejunostomy tube)

The tube goes into the stomach and then continues into the small intestine. This lets the liquid (food and medicine) to go straight into the intestine (jejunum).

If your child has a GJ, they also have a G-tube. They'll have 2 ports. Your child's care team will let you know when to use each port.



The GJ-tube starts in the stomach and continues into the small intestine. Liquid is digested by the small intestine.

# When should I get help?

# Call the surgery clinic at (615) 936-1050 right away if:

- the tube comes out before their 1st tube change
- your child starts to bleed, and you can't make it stop
- the tube is clogged, and you can't clear it (see page 12 for steps to clear a clog)
- their skin around the port is red and they have a temperature of 100.4°F (38°C) or higher
- their belly is bloated, feels hard when you gently press on it, and it does not get better after you vent (see page 13 for how to vent).

The surgery clinic's regular clinic hours are Monday to Friday, 8:00 a.m. to 5:00 p.m. If you call outside of regular clinic hours, leave a message. The surgery clinic team will call you back.

If your child needs help right away, take them to the closest ER.

# Send a message in My Health at Vanderbilt if:

- the skin around the port is red or swollen
- there are sores or pus around the port
- the skin around the port is thick and red
- there's blood around the tube, in your child's poop, or in their stomach
- they throw up during a feeding
- they have diarrhea
- the opening has gotten bigger.

The surgery team checks messages during regular clinic hours. Do not send urgent messages to them through My Health.

If you have an urgent concern, always call the surgery clinic at (615) 936-1050 right away.

# Lesson 1 Goals Check In At my child's bedside, I was able to show that I know: what to do if the tube comes out before the 1st change when to get help.

# Lesson 2: How to take care of their skin

# Your goals for this lesson

### You'll learn:

- how to clean the skin and what you supplies you need
- what to do if your child has any problems with their skin
- what to do if the feeding tube leaks
- how to protect their skin and tube.

We'll go over everything you need to know. Then you'll show us what you learned at your child's bedside.

# How do I clean their skin near the feeding tube?

It's important to keep the skin clean and dry. You should clean the skin and change the bandages around the tube at least 1 time a day. You'll need to clean it more often if it gets wet or dirty.

# Step 1: Get your supplies

- Soap and water
- Wash cloths or cotton swabs
- Split gauze and medical tape

# Step 2: Get ready

- Wash your hands with soap and water.
- Remove split gauze from around feeding tube.
- Use warm, soapy water to get 1 wash cloth or cotton swab wet.

# Step 3: Clean skin

- Use the wet, soapy swab or cloth to gently
  wipe the skin around the feeding tube. You
  can gently tip the port to the side to get the
  swab or edge of the cloth under it. But don't
  pull on the port.
- Pour a cup of warm, clear water over the skin to rinse off the soap.
- Use a new swab or cloth to pat the skin dry.

  Do not rub their skin.
- Put 1 piece of new split gauze on.



How to gently tip port to the side to clean skin

# What if there's a problem?

The skin around the port can get red, sore, or infected. Check the skin for signs of a problem each time you clean it and change the bandages.

We'll talk to you about the signs of infection. If you see any signs, call the surgery clinic at (615) 936-1050 right away.

### If their skin is red

If they don't have a fever, let your child's care team know. They'll let you know what you can use. They may ask you to use a diaper rash cream, healing ointment, or other ointment.

If their skin is red and they have a fever, call the surgery clinic right away. It may be an infection.

# If they have a bumpy rash

Call the surgery clinic. It may be a yeast infection. They'll let you know what you can use. They may ask you to use an anti-fungal cream or powder.

# If there's yellow or green liquid on the bandage

Some drainage is normal. But it can also be a sign of infection. Call the surgery clinic. They'll let you know what to do.

### If the skin is thick and red

As the skin heals, the skin at the opening of the stoma may become thick and red (granulation tissue). You should let your child's care team know. At your child's next clinic visit, they'll want to make sure the skin won't make the tube start to leak. They may ask you to put medicine on it, so it doesn't get bigger.

Sometimes it can cause some bloody drainage. This is normal.



What granulation tissue looks like

# What if the tube leaks?

The feeding tube will leak sometimes. This is OK. You can expect to see light brown liquid on the bandage. It's common to need to change the bandage 1 to 3 times a day.

# If there's a lot of liquid

This may be a sign there's a problem.

# If it happens before their 1st time tube change

Call the surgery clinic right away. They'll need to check the balloon to make sure it has enough water inside it.

# If it happens after their 1st time tube change

Check the balloon. Make sure the balloon has the right amount of water in it. If it doesn't, add more water until it does. If you're not sure how much it should have, ask your child's care team.

If it does have enough water but still leaks, call the surgery clinic right away.

# How do I protect the skin and tube?

- Don't let your child play with the port. They
  may pull it out. And they may be more likely
  to get granulated skin.
- Use medical tape on 2 sides of the port until the stoma has healed. This will help keep it in place and stop your child from pulling it out.



Use medical tape to help keep the port still while the stoma heals.

# How do I care for their mouth?

- If your child has teeth, use a soft toothbrush to brush their teeth at least 1 time a day.
- If they don't have teeth, use a damp wash cloth to wipe their gums.
- If their lips are dry, you can put lip balm on their lips.

# Lesson 2 Goals Check In At my child's bedside, I was able to show that I know: what supplies I need how to clean their skin how to check their skin for problems how to protect the skin and tube.

# Lesson 3: How to feed your child

# Your goals for this lesson

You'll learn how to:

- feed your child
- keep them safe while you feed them
- flush the tube
- give them medicine
- vent after feeding.

We'll go over everything you need to know. Then you'll show us what you learned at your child's bedside.

# How do feed my child?

# Your child's formula

Your child may be able to use a formula that is ready-to-use. Or you may have a recipe that you'll make yourself.

If you child has a recipe, you can make 1 feeding at a time or enough for 24 hours.

If you make enough for 24 hours:

- Store the formula in the fridge. Take out enough for 1 feeding at a time. Let it warm up to room temperature before you feed your child.
- Throw away any formula that was not used within 24 hours.

If your child uses a ready-to-use formula, once you open the can, use it within 48 hours. Throw away any formula you didn't used.

# Ways to make the formula flow

There are 2 ways to make the formula flow down into the tube. You can use a pump (a machine) or gravity.

# Types of feeding

- Bolus feeding: when you feed your child in the amount of time it would take them to drink the formula. This usually takes
   15 to 20 minutes. You may use a pump or gravity to make the formula flow into their tube.
- Continuous feeding: when you use a pump to feed your child over several hours.

# How to position your child

You should raise your child's head during feedings. They should not lie flat.

Your child's care team will let you know how high you should raise their head up. They may want your child to be about halfway between lying flat and sitting up (30 to 45 degree angle).

If your child is less than 1 year old and they do overnight feedings, do not use a pillow to prop their head up. You should raise the head of their bed up so they're at the right angle.

# How do I use a pump?

There are different types of pumps. You'll get your pump in the hospital and learn how to use it before your child goes home.

# 1. Get the formula ready

- Measure the amount of formula you need.
  - Do not use more formula than you'll use within 4 hours.
  - It's not good once it's been out of the fridge for more than 4 hours.
- Get a formula bag. You'll use the same bag for 24 hours.
- Open the top of the bag. Pour the formula into the bag. Close the bag.

# 2. Get the pump ready

- Hang the formula bag on the IV pole.
- There will be a tube that comes out of the formula bag. Take part of that tube and put it into the pump as your care team showed you in the hospital.

# 3. Prime the tubing

This lets you get all the air out of the formula bag tubing, so it doesn't get pumped into your child's stomach or intestine.

- Push the button on your pump that says "Prime."
- Let the formula flow through the tube until it's at the very end.

# 4. Attach the tubing to the port

- Get the extension tube from your supply kit. It has an L-shaped part at 1 end.
- Close the clamp in the middle of the extension tube and close the ends of it.
- Open the cap in your child's port (button).
- Look for the black line on the port. Then look for the line on the L-shape part of the extension tube.
- Line up those lines. Then push the L-shape part into the opening of the port.
- Turn the extension tube around so the line points in the opposite way (180 degrees or half a circle). This locks it inside the port.
- Open the other end of the extension tube.
  Attach the formula bag tubing to it.
- Open the clamp on the extension tube.

If you have an infant. You may want to let the formula flow into the extension tubing before you attach it to their port.

# 5. Start the pump

Set the pump to feed your child at the speed you need. Then push start.

# How do I do a gravity feed?

# 1. Get the formula and supplies ready

- Measure the amount of formula you need.
- Get a clean formula syringe.

### 2. Attach the extension tube

- Get the extension tube from your supply kit. It has an L-shaped part at 1 end.
- Close the clamp in the middle of the extension tube and close the ends of it.
- Open the cap in your child's port (button).
- Look for the black line on the port. Then look for the line on the L-shape part of the extension tube.
- Line up those lines. Then push the L-shape part into the opening of the port.
- Turn the extension tube around so the line points in the opposite way (180 degrees or half a circle). This locks it inside the port.
- Open the other end of the extension tube.
  Attach the tip of the syringe to it.
- Open the clamp on the extension tube.

### 3. Start to feed

- Pour the formula into the syringe.
- Hold the syringe above your child. But don't hold it too high. That would make the formula flow too fast.
- Open the clamp on the syringe and let the formula flow. Don't force the formula to flow faster.
- Add more formula to the syringe as needed.
   Add it before the syringe is totally empty so air does not get into the tube.
- It should take about 15 minutes to feed all the formula. If you go too fast, it can give your child cramps, an upset stomach, diarrhea, or make them throw up.
- Flush the tube. See page 12 to learn how.



How to use a syringe and gravity to feed your child

### How do I flush the tube?

To flush the tube, you'll use a syringe to gently push water through the tube. This will clear any leftover formula or medicine. This helps the tube not get clogged.

You should use 1 to 2 ml of warm or room temperature water.

You should flush the tube:

- before and after each bolus feeding
- before and after each medicine
- 2 times a day if your child gets continuous feeds.

# If the tube gets clogged

- Try to slowly push warm water in the tube.
   Do not force the water into the tube or put anything else in tube. Only use warm water to clear a clog.
- Wait 10 to 15 minutes.
- Try to flush the tube again.
- Repeat until the clog is gone or you've tried 4 times. If the tube is still clogged after 4 tries, stop and do not use the tube. Call the surgery clinic at (615) 936-1050.

# How do I give my child medicine in their tube?

Ask for liquid medicine for your child. If they need to take a medicine that only comes as a pill, talk to your child's pharmacist. You may be able to crush it up and add it to water. But this is not safe for all medicines.

# To give liquid medicine

- 1. Flush tube with 1 to 2 ml of water.
- 2. Use a medical syringe to put the liquid medicine in the tube.
- 3. Flush tube with 1 to 2 ml of water.
- 4. Repeat steps for each medicine your child takes. Always flush between each medicine.
- 5. Flush tube with water.

Always flush the tube between each liquid medicine you give your child. Some medicines do not mix well with formula or other medicines. If you do not flush between each type of liquid, the tube may get clogged.

If you need to give liquid medicine between feedings, you can use a medical syringe to put the medicine directly into the port.

# How do I vent their tube?

Venting lets air come out of the stomach. It's like a burp. It can help your child feel more comfortable and gag less.

### To vent

- 1. Get a syringe.
- 2. Have your child lie flat on their back.
- 3. Take the plunger out of the syringe.
- 4. Put the syringe on the port or extension tube. If you use the extension tube, unclamp it.
- 5. Hold until the air comes out of the tube and syringe. You may see bubbles in the syringe.
- 6. Once the air comes out, take the syringe off. If you used the extension tube, clamp it.



Use a syringe to let air come out of the stomach.

# Lesson 3 Goals Check In

At my child's bedside, I was able to show that I know:

- $\hfill \square$  how to raise my child's head during feedings
- give them formula
- $\hfill \square$  how to flush the tube
- give them medicine
- $\square$  how to vent the tube.

# Keep your child safe

# Things to do

- Clean and check skin at least 1 time a day.
- Change bandage when it gets wet or dirty.
- Tell your child's care team if they have any problem with their skin.
- Tell your child's care team if the tube leaks.
- Raise their head during each feeding.
- Vent the tube if they're fussy or their stomach looks bigger than normal.
- Flush the tube:
  - before and after each bolus feeding
  - before and after each medicine
  - 2 times a day if your child gets continuous feeds.
- Throw away formula you mixed after 24 hours. Throw away ready-to-use formula after 48 hours.
- If your child is less than 1 year old, put them on their back when they sleep. This is the safest way for them to sleep unless their care team told you to put them in a different position.

# Things not to do

- Do not try to put the tube back in if it has not been changed for the 1st time. Take your child to the hospital to have it put back in.
- Do not try to force anything in the tube if it's clogged. Gently push warm water to unclog it.
- Do not let your child play with the port. They
  may pull it out. And they may be more likely
  to get granulated skin.
- Do not leave the extension tubing attached to the port when you're not using it.
- Do not use formula that has been out of the fridge for more than 4 hours.

# Words to know

# Feeding tubes and parts

- Balloon: the part at the end of the feeding tube that goes inside the body. It sits inside the stomach to hold the tube in place.
- **GJ-tube** (gastrojejunostomy tube): feeding tube that goes into the small intestine (jejunum).
- **G-tube** (gastrostomy tube): feeding tube that goes into the stomach.
- Port: the part at the end of the tube that stays outside the body. It's the part of the tube you'll see. It will have 1 or more openings.

# Types of feedings

- Bolus feeding: when you feed your child
  in the amount of time it would take them
  to drink the formula. This usually takes
  15 to 20 minutes. You may use a pump
  (a machine) or gravity to make the formula
  flow into their tube.
- Continuous feeding: when you use a pump to feed your child over several hours.
- Gravity feeding: when you use gravity, not a pump, to make the formula flow into their tube.

### Care

- Flush: a way to clear out the tube. You gently push water through the tube, so it does not get clogged.
- Granulation tissue: a type of skin that builds up around the tube. This skin is thick and red. This is common. We may give your child medicine if it happens.
- Venting: lets out air from the stomach. It's like a burp. You put an empty syringe on to the tube to let air come out.

# Supplies

- Medical tape: special tape that is safe to use on skin around the feeding tube.
   Mepitac is 1 type of medical tape you can use.
- Mepilex: a soft, foam bandage (dressing)
  used to cover wounds.
- **Split gauze:** a square piece of gauze that has a cut in the middle. The cut lets you slide the gauze around the port.
- Syringe (catheter-tip): a tool that lets formula flow during feedings and lets air out of the stomach during venting.

Monroe Carell: (615) 936-1000

Surgery Clinic: (615) 936-1050

