

# *Your Guide to* Pediatric Home Tube Feeding



NestléHealthScience™

Nestle Health Science has made every effort to include in this Guide only information that it believes to be accurate and reliable at the date of publication. This Guide is applicable to children ages 1-16 years and contains information from a variety of sources including practice-based resources, guidelines from professional organizations, and experiences of healthcare professionals who have managed pediatric patients on home tube feeding. Information provided in this Guide is for education purposes. It is not intended to replace the advice or instruction of your healthcare professionals, or to substitute medical care. Contact a qualified healthcare professional if you have any questions regarding your tube feeding product, prescription, supplies or issues related to any of these.

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# Introduction to TUBE FEEDING AT HOME

## It's good to be home

As you get used to being home with your child who is using a feeding tube, this *Pediatric Home Tube Feeding* guide will help you and your family understand how to manage their tube feeding.

## What is tube feeding?

Tube feeding is a way of providing nutrition to a child who cannot eat and drink enough to meet his or her nutritional needs in order to grow and be as healthy as possible.

- Tube feeding products are liquid food, often called formula, which is given through a special tube to make sure your child gets the nutrition and fluid they need.
- Just like regular food, tube feeding formula will provide all the essential nutrients - calories, protein, carbohydrates, fats, vitamins and minerals.
- Your doctor may also want your child's medication to go through the feeding tube.

## Why does your child need tube feeding?

Children may need a feeding tube for a number of reasons, such as:

- when they are unable to get enough nutrition through eating and drinking by mouth to enable them to gain weight or achieve catch-up growth
- when they are unable to digest or absorb food normally
- when chewing and/or swallowing is difficult or unsafe
- when food or drink comes back up from the stomach (called reflux)
- after surgery or medical treatments, when it may be difficult or impossible to eat for a period of time

Your healthcare team will set up a plan to monitor how your child is doing with their tube feeding, including tracking his or her weight and height to make sure the nutrition in the tube feeding is able to support growth and your child's overall needs.

## How this booklet can help

As part of the training you will receive for tube feeding at home, this booklet can support what your doctor, nurse and dietitian have told you.

## Making your home tube feeding a comfortable experience

For most families, tube feeding is a change that needs a certain amount of time and persistence to get used to at home. There are ways to help make this adjustment easier, such as:

- Talk to your child about their new way of eating to help him or her understand what the tube feeding is all about. More information on helping your child adjust may be found in the section "Tips to Help You and your Child with Tube Feeding".
- Talk to your friends and family about your child's tube feeding. You may even want to teach them how to help with caring for your child's tube feeding.
- Ask your healthcare professional to help you arrange your child's feeding schedule so he or she can receive the tube feeding formula during family meal times.
- If you want your child to have tube feedings in private or at other times, be sure to help your child take part in other family and social activities.

Talk to your healthcare professional about any questions you have about living with your child's feeding tube at home, including things such as bathing, exercise, playing with others, or travel. Your healthcare professional can also help you to create a feeding plan if your child is attending school.



## Questions about **YOUR CHILD'S FEEDING TUBE**

*"Tube feeding has been a huge learning experience! I constantly think about the nutritional aspect of my daughter's diet, and wonder if she's getting enough or not. Our pediatric nutritionist has been one of my greatest resources ... There are a lot of questions when your child is being tube-fed. I am in regular contact with her feeding 'team,' and I don't hesitate to pick up the phone and call when I have a question."*

*—Cathy R., mom of Breeauna,  
age 6*

### What should I say if people ask about my child's feeding tube?

You can answer this question in many different ways.

You may say something simple like:

*"My child is not able to eat, so this is the way I feed her."*

Or if your child is having medical treatments or problems swallowing or digesting food you might say:

*"My child is having trouble swallowing and needs to get her food this way."*

*"My child is having medical treatments which make it hard to eat. I use this feeding tube to give her the nutrition she needs."*

*"My child's stomach is not working properly, so she needs this tube to feed herself."*

*"My child's body has a hard time digesting foods. We use this feeding tube and special liquid food to get the nutrition she needs."*

## Nutrition Matters

The goal of providing nutrition to a child is to support growth and development. This may come from food or fluid taken by mouth, a tube feeding or sometimes both. A healthy diet is more than just "food" – it provides fuel as well as the building blocks to keep or restore health and to help with healing.

Maintaining a healthy diet and good nutrition is important for everyone, but is crucial to the child who has an illness, is receiving certain medical treatments, is recovering from surgery, or who is not gaining weight and growing like other children the same age. A child's body may be working extra hard to restore good health, and this may increase his or her nutrient needs. Some children may also have special needs such as digestive problems or food allergies that affect their food or formula choices. Your health care professional will consider all of these factors when deciding the type of formula and amount needed each day.

Good nutrition is important to support your child's needs. The nutrients needed by the body include:

- carbohydrates
- protein
- fat
- vitamins
- minerals
- water

These nutrients work together to maintain and build body tissue and provide energy for your child's body. Normally, these nutrients are provided by eating a variety of foods. However, because of your child's special needs, he or she is getting their nutrition in a liquid form through a tube.

There are many ways to make sure your child is getting the right types and amounts of nutrients, including:

- Growth charts – tracking weight and height for your child over time
- Blood tests – to see blood levels of certain factors like iron, proteins or blood glucose
- Checking skin, bones, hair and teeth for overall health and development

Your healthcare team will set up a care plan to monitor how your child is doing with their tube feeding, including tracking his or her weight and height to make sure the nutrition in the tube feeding is supporting your child's growth and overall needs.

*If my child is on a feeding tube, can she still drink or eat by mouth?*

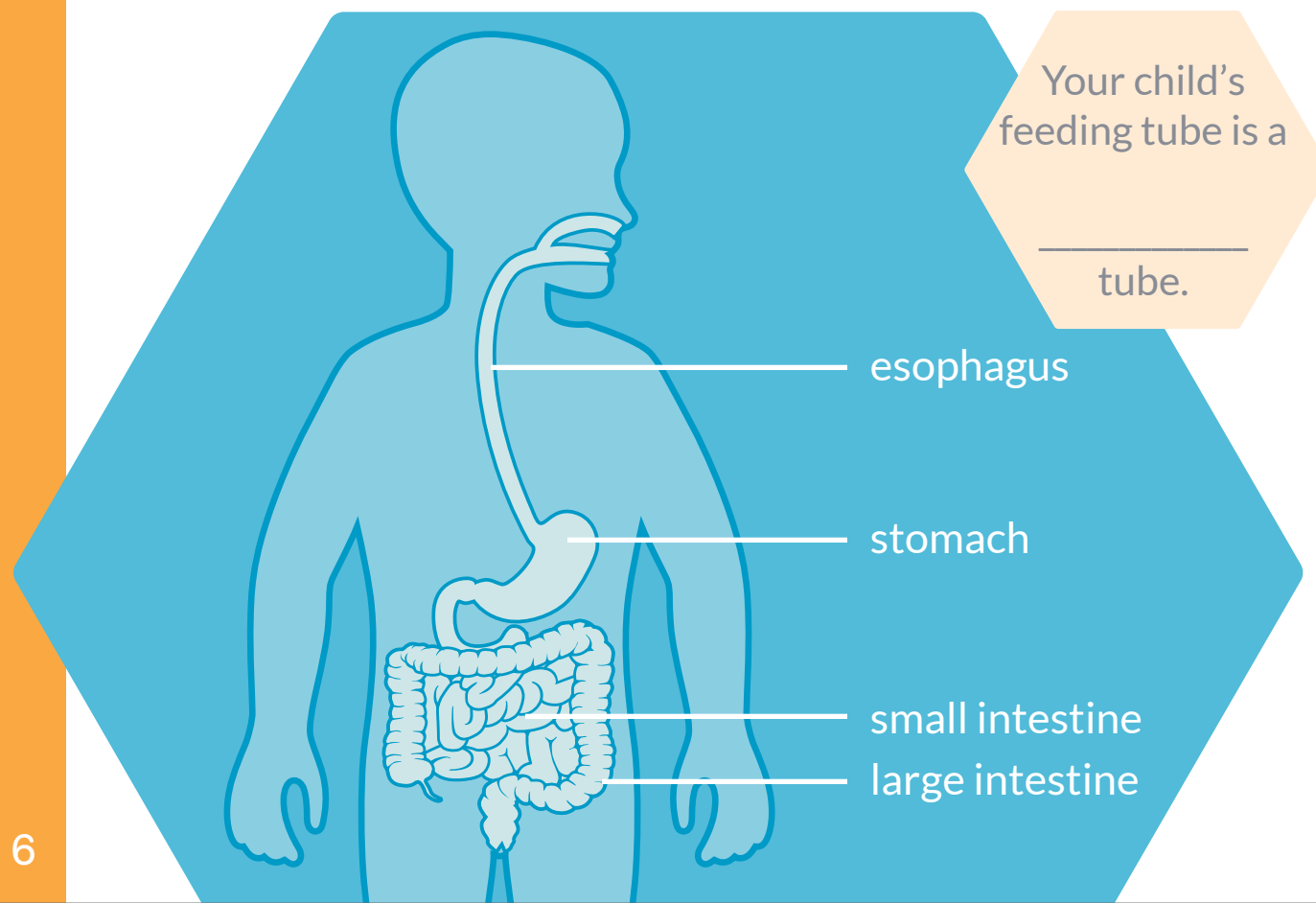
Taking foods or fluids by mouth while receiving nutrition from a tube feeding may be possible and may help your child to learn the skills needed to eat and drink at a later time. Always speak to your healthcare provider before giving any food or fluid to your child by mouth to be sure it is safe.

# The Location of YOUR CHILD'S FEEDING TUBE

## Where is the feeding tube in your child's body?

There are many different types of feeding tubes used to give tube feeding formula, and there are several different places where these feeding tubes may be located in the body. Each of these places allows the nutrients in the formula to be used by your body, just like eating a regular meal:

- **Nasogastric** or '**NG-Tube**': The feeding tube goes through the nose, down the esophagus or food tube, and ends in the stomach.
- **Nasojejunal** or '**NJ-Tube**': The feeding tube goes through the nose, down the esophagus or food tube, continues through the stomach, and ends in the small intestine.
- **Gastrostomy** or '**G-Tube**': The feeding tube goes through a small opening in the skin directly into the stomach.
- **Jejunostomy** or '**J-Tube**': The feeding tube goes through a small opening in the skin into the jejunum or small intestine.



# Feeding METHODS

There are different ways to provide a tube feeding.

Tube Feedings may be timed or planned. They can be:

- **Continuous**: formula is flowing all the time or for many hours during the day and/or night
- **Intermittent** or **Bolus**: formula is given at meal times or with breaks during the day
- or a mix of these two

Depending on the tube feeding plan, the formula may be delivered by:

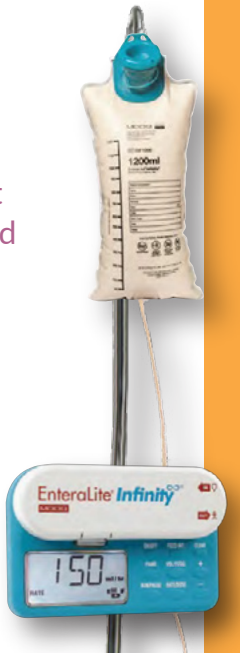
- **A feeding pump** (for continuous feeding and some intermittent feedings)
- **Gravity** (for intermittent feedings)
- **Syringe** (for bolus feeding)

A feeding method (the timing and delivery) may be chosen because of:

- The type and location of the feeding tube your child has
- The reason your child needs the tube feeding
- How often your child needs tube feeding
- How you manage your child's tube feeding at home

Your healthcare team has chosen the method they believe will work best for you and your child at home to make sure he or she gets the nutrition needed.

A feeding pump is a special device that controls the timing and amount of formula given. Formula flows from a feeding bag or pre-filled container through tubing that runs into the pump and then into your child's feeding tube.



Gravity feeding uses a feeding bag and tubing which you hang on a pole above the level of your child's stomach. Gravity will move the formula from the bag through the feeding tube.



Syringe feeding uses a large (60 mL) syringe to deliver the formula. The formula can be gently pushed into your child's feeding tube using the syringe plunger or it can flow from the syringe into your child's feeding tube using gravity.



The following section, *Managing Your Child's Tube Feeding*, will cover the different feeding delivery methods and the equipment needed.

## Managing YOUR CHILD'S TUBE FEEDING

### Checking the placement of your child's feeding tube

(If instructed by your healthcare professional)

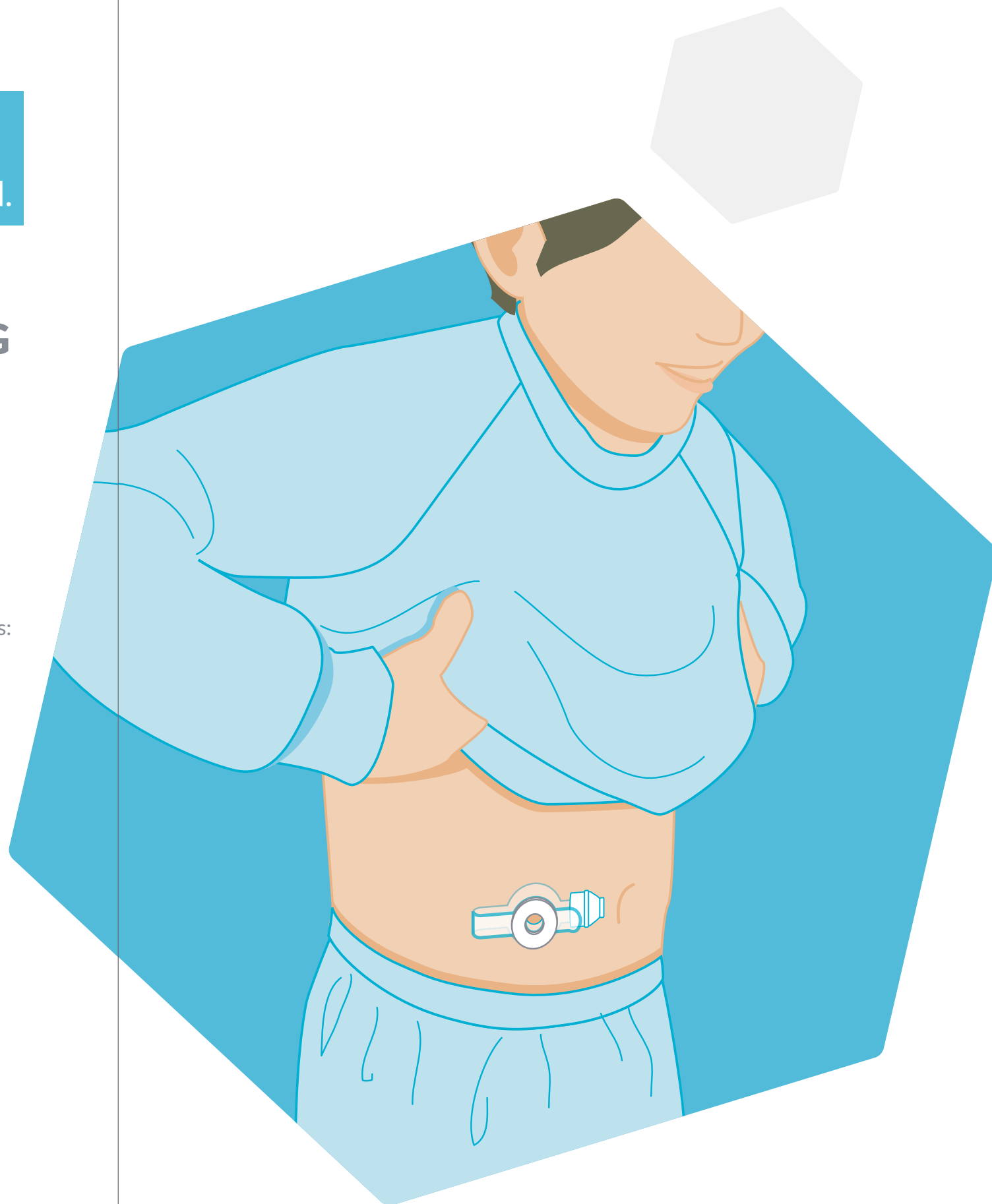
You may be asked to check the placement of your child's feeding tube at home before you start a feeding - or less often such as once a day or a few times a week.

If you have been asked to check the position of the tube, follow these steps:

1. Wash your hands.
2. For a **nasogastric** or **nasojejunal tube**: check the proper tube position as instructed by your healthcare professional. There may be a special mark drawn on the tube or a certain length it should be from the end of your child's nose.

For a **gastrostomy** or **jejunostomy tube**: use a ruler or non-stretchy tape measure to measure the number of inches/centimetres from the spot where the tube exits your child's body to the end of the tube.

3. Compare the number with previous measurements. If there are more than \_\_\_\_\_ inches/centimetres difference, call your child's healthcare professional. Do not begin the next feeding.



# Using syringe feeding

## Gather your supplies

- Formula
- Clean cup or container, if needed
- 60 mL syringe
- Water at room temperature

## Get set up

1. Wash your hands
2. Wipe the top of the formula container with a clean, wet cloth
3. Shake the formula container gently
4. Check your child's 'feeding schedule' for how much formula to use

## Starting the feeding

1. Get your child into a comfortable position – have him or her sit upright or lie with the head of the bed raised to 45 degrees -about the height of 2 pillows
2. Open your child's feeding tube
  - Fold over and pinch or clamp the end of the feeding tube to stop the flow. Then uncap the tube.
3. Flush your child's feeding tube with \_\_\_\_ mL of water
4. Close or recap your child's feeding tube

For the next steps, continue to page 12



Use either method A or B below,  
as directed by your healthcare professional:

## METHOD A

### BY GRAVITY - POURING FORMULA INTO THE SYRINGE

5. Open your child's feeding tube
  - Fold over and pinch or clamp the end of the feeding tube to stop the flow. Then uncap the tube.
6. Attach the syringe to the end of your child's feeding tube.  
Unfold the tube to start the flow.
7. Pour formula into the syringe
8. Let the formula flow into your tube by gravity. Holding the syringe higher or lower will control the feeding rate.
9. Continue refilling the syringe until your child's entire feeding is given
  - This entire process may take a few minutes or you may space out the syringe feeding over a longer period of time
  - Talk to your healthcare professional about how long your child's tube feeding should take to run by gravity
10. Take the syringe off your child's tube - fold over and pinch the end of the feeding tube to stop the flow and recap the tube
11. After feeding, flush your child's feeding tube with \_\_\_\_ mL of water
12. Close or recap the feeding tube
13. Clean, rinse and dry all supplies as directed by your healthcare professional

## METHOD B

### PUSHING FORMULA WITH THE SYRINGE

5. Pour your child's formula into a clean cup or container
6. Draw the formula up into the syringe
7. Open your child's feeding tube
  - Fold over and pinch or clamp the end of the feeding tube to stop the flow. Then uncap the tube.
8. Attach the syringe to the end of your child's feeding tube
9. Gently push the formula into the tube with the syringe plunger
10. Take the syringe off your child's tube - fold over and pinch or clamp the end of the feeding tube to stop the flow and recap the tube
11. Repeat steps 6 to 10 until your child's entire feeding is given
  - This entire process may take a few minutes or you may space out the syringe feeding over a longer period of time
  - Talk to your healthcare professional about how long your child's tube feeding should take to feed by a syringe
12. After feeding, flush your child's feeding tube with \_\_\_\_ mL of water
13. Close or recap the feeding tube
14. Clean, rinse and dry all supplies as directed by your healthcare professional



# Using Gravity Feeding

## Gather your supplies

- Formula
- Feeding bag and tubing
- Pole
- 60 mL syringe
- Water (room temperature)

## Get set up

1. Wash your hands
2. Wipe the top of the formula container with a clean, wet cloth
3. Shake the formula container gently.
4. Close the tubing on the feeding bag by closing the roller clamp
5. Pour the formula into the feeding bag and close the top of the bag
  - Check your child's 'feeding schedule' for how much formula to use
6. Hang the feeding bag on the pole so it is at least 18 inches / 45 centimetres above the level of your child's stomach
7. Start the flow of formula through the feeding bag tubing by opening the roller clamp
8. Let the formula flow to the tip of the tubing
9. Close the roller clamp



# Starting the feeding

1. Open your child's feeding tube
  - Fold over and pinch or clamp the end of the feeding tube to stop the flow. Then uncap the tube.
2. Flush your child's feeding tube with \_\_\_\_ mL of water
3. Attach the tip on the end of the feeding bag tubing to the feeding tube
4. Get your child into a comfortable position – have him or her sit upright or lie with the head of the bed raised to 45 degrees (about the height of 2 pillows).
5. Open the roller clamp to adjust the flow rate to \_\_\_\_ drips or \_\_\_\_ mL per \_\_\_\_ seconds
6. Each feeding should take about \_\_\_\_ minutes
7. After the feeding, close and take off the feeding bag tube
  - You may be asked to pour \_\_\_\_ mL of water into your child's feeding bag and run this into his or her body before taking off the feeding bag tube
8. Flush your child's feeding tube with \_\_\_\_ mL of water
9. Close the feeding tube
10. Clean, rinse and dry all supplies as directed by your healthcare professional
11. Replace your child's feeding container and tubing as advised by your healthcare professional



# Using a Feeding Pump

## Gather your supplies

- Formula
- Feeding bag and tubing
- Feeding pump
- Pole
- 60 mL syringe
- Water (room temperature)

## Get set up

1. Wash your hands
2. Wipe the top of the formula container with a clean, wet cloth
3. Shake the formula container gently
4. Pour the formula into the feeding bag and close the top of the bag – make sure the roller clamp is closed
  - Check your child's 'feeding schedule' for how much formula to use
5. If using an IV pole, hang the feeding bag on the pole above the feeding pump
6. Since every pump is different, follow the instructions given by your healthcare professional to use your child's feeding pump and 'prime' the tubing. (Priming means to fill the tubing with formula before it is attached to the feeding tube.)



## Starting the feeding

1. Get your child into a comfortable position – have him or her sit upright or lie with the head of the bed raised to 45 degrees - about the height of 2 pillows
2. Open your child's feeding tube
  - Fold over and pinch or clamp the end of the feeding tube to stop the flow. Then uncap the tube.
3. Flush your child's tube with \_\_\_\_ mL of water
4. Attach the tip on the end of the feeding bag tubing to the feeding tube
5. Set the flow rate on the pump to \_\_\_\_\_ mL per hour
6. If needed, open the roller clamp on the feeding bag tube
7. Start your child's feeding pump
8. After the feeding, take the feeding bag tube off of the feeding tube
9. Flush your child's tube with \_\_\_\_ mL of water
10. Close the feeding tube
11. Clean, rinse and dry all supplies as directed by your healthcare professional
  - If you are pouring formula into a feeding bag container for your child's tube feeding, check with your healthcare professional about how long the feeding formula should "hang" or stay in the feeding bag and tubing at room temperature
12. Replace the feeding container and tubing as advised by your healthcare professional

*"When we first found out that our son needed to be tube-fed, we were mostly just scared and wondering if he would still be able to eat by mouth. If he would ever be [able to] transition off the tube. Would we ever be able to leave the house? ... At first, we were not at all comfortable with administering our son's tube feedings. We only had two days of watching at the hospital, and we didn't have anything to practice with. We had no idea what we were doing. But now, I am able to train my extended circle of care.*

*—Jacquelyn F., mom of Rafael, age 6*

## How to Give Water or Medications WITH A SYRINGE

Water is part of your child's formula, but extra water and sometimes medications are needed to keep their body healthy and the feeding tube working well.

- Your child's healthcare professional will tell you how much water or medication to take.
- Your child's healthcare professional will tell you which medications you can crush, or if there are liquid medications that can be used.

### Check with your child's nurse, doctor or pharmacist to find out about:

- Which medications should not be crushed
- How to crush medications – if you are asked to do this
- How much water to mix with their medication
- Which medications should not be given together
- If there are any other special instructions about giving medications through your child's feeding tube

When giving water and medications, follow the steps below.

When giving water only, start at step 2.

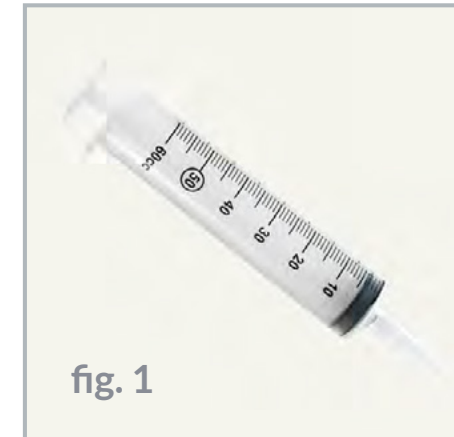


fig. 1

1. Using a 60 mL syringe, flush your child's feeding tube with 15-30 mL of warm water before giving medication, unless you are told something different by your healthcare professional. Always follow your healthcare professional's instructions. See Figure 1.

2. Using a 60 mL syringe, draw up the right dose of medication or water into the syringe. Open your child's feeding tube and attach the syringe to the feeding tube. See Figure 2 and Figure 3.



fig. 2

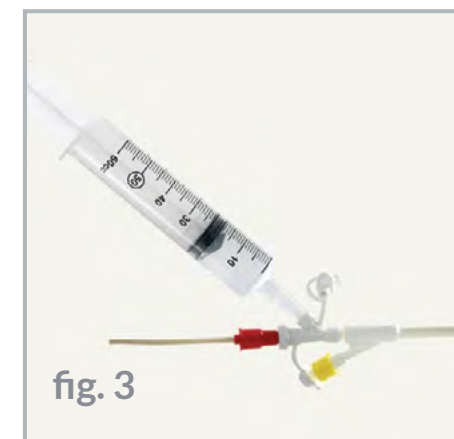
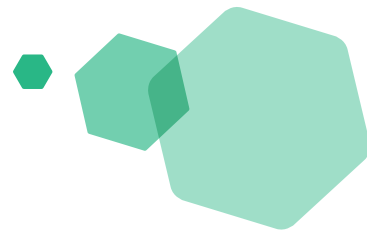


fig. 3

3. Gently push the water or medication into the tube. See Figure 3.
4. Take the syringe off your child's feeding tube and refill the syringe with warm water until the all of the water you need is given, or to flush all the medication out of the syringe.
5. Close the feeding tube when finished and place the cap back on the tip of the syringe.



## PERSONAL CARE

### Your child's mouth

Keeping your child's mouth clean is important when tube feeding, even if he or she is not eating and drinking. Your healthcare professional may recommend they brush their teeth each day and use lip balm to help keep their lips moist.

Ask about the best way to keep your child's mouth clean and which products you should use.

Follow the advice from your healthcare professional.

#### *Instructions*

### Your child's nose

If your child is taking their feeding through a nasogastric tube, the tube passing through their nose may cause mild irritation or you may notice some thick, crusty mucus in the nose.

Ask about the best way to take care of your child's nose.

Follow the advice from your healthcare professional.

#### *Instructions*

### The tube site

If your child has a gastrostomy or jejunostomy tube, taking care of the skin around the area where the tube enters his or her body is very important.

Ask about the best way to take care of the tube site.

Follow the advice from your healthcare professional.

#### *Instructions*

## ORAL STIMULATION

Eating and drinking food and fluids by mouth is an important part of a young child and toddler's learning and development. Oral stimulation may help a young child to learn or maintain how to chew, drink or suck. Ask your healthcare professional for ideas about providing your child with safe ways to chew or suck.



# TUBE FEEDING FORMULAS

There is a wide range of tube feeding formulas which may come in different types of packaging. Your healthcare professional will consider your child's unique needs when choosing a formula – this includes not only their nutrition needs but also the feeding method you are using at home. Similar products in the same categories below are available for adults and may be recommended for children over 13 years of age.

## Types of Formulas for Children 1 to 13 years of age

### Standard Formulas

Standard pediatric formulas are nutritionally complete and are designed for children ages 1-13 years who have normal digestion. Some of these formulas can be used for both tube feeding and oral feeding, and some contain fibre.

There are also pediatric formulas available which contain real food ingredients such as chicken, vegetables and fruit along with other vitamins and minerals to create a nutritionally complete formula.

*Nutren Junior, Resource Kid Essentials 1.5 and Compleat Pediatric are examples of standard formulas.*



### Semi-elemental/Peptide-based Formulas

As with standard formulas, pediatric semi-elemental formulas are nutritionally complete. Semi-elemental formulas are different because they contain some nutrients, such as protein and fat, which are 'broken down' into smaller units to make them easier to digest. This is the reason these formulas are also called "peptide-based" formulas – because "peptides" is the name used to describe smaller units of protein. Some semi-elemental/peptide-based formulas can also be used for both tube feeding and oral feeding, and may contain ingredients such as fibre.

*Peptamen Junior is an example of a semi-elemental/peptide-based formula.*



### Specialized Formulas

Specialized formulas are available for children with particular needs such as those with Crohn's disease, multiple food allergies or those with severe issues digesting fat and protein.

*Modulen IBD and Vivonex Pediatric are examples of specialized formulas.*



### Modular Products

Modular products are individual nutrients that may be added to formula for children who require additional nutrition. Modular products provide extra protein, fat or calories without adding much volume to the formula itself. If modulars are needed, your healthcare professional will teach you how to use them and provide a recipe if needed.

*Microlipid, MCT Oil and Beneprotein are examples of modular products.*



## FORMULA PACKAGING

Tube feeding formulas come in different types of packages:

- Ready-to-use liquids in 'drink box' packaging, bottles, or cans
- Powder in a can or small packet that is prepared by mixing with water

All of these formulas are fed using either a syringe or container that the formula is poured into before feeding.



## FORMULA HANG TIME

The term "formula hang time" refers to how long a tube feeding formula should remain at room temperature for feeding – after the formula package has been opened or the original package seal has been broken. The following are commonly suggested hang times:

- Up to 8 hours\* for ready-to-use liquids
- Up to 4 hours\* for powders or formulas that have been mixed with water or other modular products

\*Important Note:

Always check with your healthcare professional about the formula hang time for your child's tube feeding formula. A shorter open-time may be recommended for your child, depending on his/her medical condition.

*Do I need to refrigerate my child's formula before feeding?*

No. Most often, tube feeding formula is stored and used at room temperature.

If a liquid formula package is opened and not used right away, it should be kept in the refrigerator for up to 24 hours.

## Storing Your Child's Formula AT HOME

The following information is a general guide. The formula package or your healthcare professional may provide other instructions for your child's particular formula.

### Liquid Formulas

- Packages that have not been opened can be stored at room temperature.
- Once a formula package is opened it should be used right away OR covered and stored in the refrigerator. Use it within 24 hours. If not used in 24 hours, throw it away.

*Should I shake liquid feeding formula before using?*

Yes. Always gently shake unopened liquid formula packages before using.

### Powdered Formulas

- Store powdered formula in a cool, dry place.
- Check the package to see how long to keep the powdered formula after it is opened.

Check the expiry date on your formula. Throw away formula that is past its expiry date.

*Will using cold formula upset my child's stomach?*

Cold formula may upset your child's stomach. You can take refrigerated formula out of the refrigerator for 30 minutes to slowly warm up to room temperature before feeding.

# Feeding INTOLERANCE

When your child first starts a tube feeding, it may take a few days for their body to adjust to the formula and feeding routine. But there are times when he or she simply may not tolerate the feeding formula you have been asked to use – your child may feel unwell and not able to take all of the formula each day. This can become a problem if your child is not able to get the nutrition and water needed, or if your child is having unpleasant symptoms that make him or her feel unwell.

Feeding intolerance is often talked about by the signs or symptoms children have – which may vary from feeling full and having a swollen belly or abdomen to vomiting or diarrhea. Being on a tube feeding does not mean that your child should feel uncomfortable during or after taking their formula.



## Tube Feeding Intolerance Checklist

You can use the checklist below to help see if your child may be suffering from tube feeding intolerance.

Check the items below that tell how your child is feeling. It helps to add notes to better describe how often the symptoms occur and how long they last.

Check all that apply

Notes on severity, frequency and duration

Nausea (your child feels sick to his/her stomach)

Vomiting

Reflux (feeling like stomach contents are coming back up to his/her throat)

Feeling of Fullness

Bloating or swollen belly/abdomen

Diarrhea/loose stools

Constipation

Feedings are being stopped or you need to slow down the rate of feedings because your child feels unwell or is irritable/fussy

If you checked one or more of the above, your child may have tube feeding intolerance.

Talk to your healthcare professional about how to manage these symptoms and if there may be another feeding formula to help make your child's feedings easier and more comfortable.

You may also find ideas in the next section on 'Problem Solving' to help manage your child's tube feeding at home.

# Problem SOLVING

## When things do not seem right

Sometimes your child may experience problems when tube feeding. The table on the next few pages provides information about some of the more common problems, possible causes and some steps you may take. The information provided in this table is not intended to replace the advice or instruction of your child's healthcare professionals, or to substitute medical care. If you have a problem, or have more questions about your child's tube feeding, be sure to talk to your healthcare professional.

PROBLEM	POSSIBLE CAUSE	WHAT TO THINK ABOUT
<b>Nausea and/or Vomiting and/or Reflux</b> (feeling like your stomach contents are coming back up into the throat)	<ul style="list-style-type: none"> <li>• Feeding too quickly</li> <li>• Slow digestion in the stomach</li> <li>• Other stomach/digestive problems or illness</li> </ul>	<ul style="list-style-type: none"> <li>• Slow or stop the feed until your child is comfortable. If needed, delay the next feeding by 15-20 minutes and restart slowly.*</li> <li>• Slow down feed rate*</li> <li>• Sit your child upright or have him/her lie at a 45 degree angle (about the height of two pillows) during the feeding and for 30 to 60 minutes after the feeding. Do not lie flat during or just after a feeding.</li> <li>• Check with your healthcare professional to see if your child should change to a special formula that may be easier to digest and absorb</li> <li>• Speak to your healthcare professional if this problem continues</li> </ul>
<b>Diarrhea</b> (frequent, loose, watery or liquid stools)	<ul style="list-style-type: none"> <li>• Medication side effects</li> <li>• Formula is being fed too fast</li> <li>• Formula may be spoiled by bacteria</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your doctor or pharmacist about your child's medications</li> <li>• Slow down the feeding rate*</li> <li>• Do not use formula that has been opened and left at room temperature for longer than recommended on the formula label</li> <li>• Do not use formula that has been opened and left in the refrigerator for longer than 24 hours</li> <li>• Wash your hands well, and use clean supplies/equipment</li> <li>• Replace your child's feeding container and tubing as directed by your healthcare professional</li> </ul>

Continues on next page

PROBLEM	POSSIBLE CAUSE	WHAT TO THINK ABOUT
<i>Continued from previous page</i> <b>Diarrhea</b> (frequent, loose, watery or liquid stools)	<ul style="list-style-type: none"> <li>• No fibre or not enough fibre, in your formula</li> <li>• Intolerance to the formula</li> <li>• Your child may have another illness, flu or infection</li> <li>• Your child's feeding tube may have moved out of place</li> </ul>	<ul style="list-style-type: none"> <li>• Check with your healthcare professional about changing to a formula that has fibre</li> <li>• Check with your healthcare professional to see if your child should change to a special formula that may be easier to digest and absorb</li> <li>• Speak to your healthcare professional if this problem continues for more than 2 days</li> </ul>
<b>Bloating or swollen belly/ abdomen; Stomach cramps; Feeling of fullness</b>	<ul style="list-style-type: none"> <li>• Formula is being fed too fast</li> <li>• Formula is too cold</li> <li>• Too much formula</li> <li>• Lying flat while taking the feeding</li> <li>• Exercising or too much activity or play right after a feeding</li> <li>• Intolerance to the formula</li> </ul>	<ul style="list-style-type: none"> <li>• Slow down the feeding rate*</li> <li>• Use stored, unopened formula at room temperature for feedings. If you have opened formula in the refrigerator, remove for 30 minutes before feeding your child.</li> <li>• Make sure your child is taking the right amount of formula and/or feeding rate</li> <li>• Sit your child upright or have him/her lie at a 45 degree angle (about the height of two pillows) during the feeding and for 30 to 60 minutes after the feeding. Do not allow him or her to lie flat during or just after a feeding.</li> <li>• Ask your healthcare professional to review your child's formula. You may need to switch him/her to a formula that has more calories in less volume or to a special formula that may be easier to digest and absorb.</li> <li>• If asked to do so, vent the tube (letting the air out by opening the feeding tube tip) as taught by your healthcare professional to make your child more comfortable</li> </ul>

\* If you have slowed the formula flow rate this may reduce the amount of formula, water and nutrition your child is getting. Check with your healthcare professional if you are not able to return to your child's original rate after 1 or 2 days and you are unable to give the amount of formula and water indicated in your child's feeding schedule.



PROBLEM	POSSIBLE CAUSE	WHAT TO THINK ABOUT
<b>Constipation</b> (bowel movements occur less than usual or are hard, dry and painful or difficult to pass)	<ul style="list-style-type: none"> <li>You are not giving enough fluid or water</li> <li>No fibre, or not enough fibre, in your child's formula</li> <li>Not enough exercise or activity</li> <li>Medications</li> </ul>	<ul style="list-style-type: none"> <li>Give more water through your child's feeding tube if advised by your healthcare professional</li> <li>Check with your doctor or dietitian to see if your child should change to a formula that contains enough fibre</li> <li>Help your child be more active - if this is possible (check with your doctor)</li> <li>Talk to your doctor or pharmacist about your child's medications</li> </ul>
<b>Dehydration</b> (the amount of water in the body has dropped below the level needed for normal body function); <b>Passing less urine/dark yellow urine;</b> <b>Feeling thirsty</b>	<ul style="list-style-type: none"> <li>You are not giving enough fluid or water</li> <li>Illness with diarrhea, fever, heavy sweating</li> </ul>	<ul style="list-style-type: none"> <li>Make sure your child is taking the right amount of water every day before and after their feedings</li> <li>Talk to your healthcare professional to make sure your child is getting the right amount of water each day</li> </ul>
<b>Gaining weight quickly</b>	<ul style="list-style-type: none"> <li>You may be giving too much fluid or water</li> <li>You may be giving too much formula</li> </ul>	<ul style="list-style-type: none"> <li>Make sure your child is taking the right amount of formula and water every day</li> <li>Talk to your healthcare professional to see if your child needs to change the amount of formula and water each day</li> </ul>
<b>Losing weight</b>	<ul style="list-style-type: none"> <li>You may not be giving enough calories</li> </ul>	<ul style="list-style-type: none"> <li>Make sure your child is taking the right amount of formula every day</li> <li>Talk to your healthcare professional to see if your child needs to change the amount or type of formula he/she is taking</li> </ul>

PROBLEM	POSSIBLE CAUSE	WHAT TO THINK ABOUT
<b>Aspiration</b> (foods or liquids pass into the airway or lungs); <b>Sudden coughing or trouble breathing</b> during feeding or right after feeding	<ul style="list-style-type: none"> <li>Your child's formula may be coming back up from the stomach and it could be breathed into their lungs</li> <li>Lying flat during feeding</li> <li>Illness such as a chest infection or pneumonia</li> </ul>	<ul style="list-style-type: none"> <li>Sit your child upright or have him/her lie at a 45 degree angle (about the height of two pillows) during the feeding and for 30 to 60 minutes after the feeding. Do not allow him or her to lie flat during or just after a feeding.</li> <li>If symptoms continue, call your doctor or go to the hospital</li> </ul>
<b>Blocked feeding tube</b> or formula will not run through the feeding tube	<ul style="list-style-type: none"> <li>There may be a kink or bend in your child's feeding tube or the feeding set</li> <li>Formula or medication may have blocked the tube</li> </ul>	<ul style="list-style-type: none"> <li>Check the feeding tube and feeding set to make sure the tubing is not bent or kinked</li> <li>Flush the tube with warm water before and after feeding or medications</li> <li>Do not give pureed foods or other liquids through the tube before talking with your health care professional</li> <li>Do not mix anything new into the formula without consulting your healthcare professional</li> <li>Use only liquid or finely crushed medicine dissolved in water</li> <li>If your child's tube is blocked, do not try to remove the blockage yourself. Consult with your healthcare professional for advice on what to do next.</li> </ul>
<b>Feeding tube falls out</b>	<ul style="list-style-type: none"> <li>Your child's tube may have come out by accident</li> </ul>	<ul style="list-style-type: none"> <li>Cover the opening with a clean cloth or towel (if you have a gastrostomy or jejunostomy tube which goes directly through the skin into your child's stomach or small intestine)</li> <li>Call your healthcare professional or go to the nearest emergency department with your child's feeding tube</li> </ul>

## Tips to Help You and Your Child WITH TUBE FEEDING

Being well informed and knowing what to expect – including the fact that there can always be surprises – will help both you and your child become comfortable with tube feeding. In no time at all, you will both become tube feeding experts! Here are some additional points to guide you:

- Being positive about the tube feeding can help your child adjust and help older children see the benefits of tube feeding. Talk to your family and friends about your child's tube feeding to help make the transition easier too.
- When adjusting to tube feeding, try to maintain as much of your child's usual routine as possible. If family dinners and story time are part of each day, work these activities into the tube feeding routine at home. Ask your healthcare professionals for help with this process.
- Expect that social times, like being at school or going to parties may bring up food-related questions. Speaking to your child's friends and teachers ahead of time will help your child be ready for these occasions. Also talk to your child about common questions that may come up so that he/she can provide answers on their own.
- Older children may have concerns or may worry about their body image with a feeding tube. Expect this, and talk with your child often to uncover any fears or concerns to address early on.
- Keep all instructions for the tube feeding and contact information in one central place. You may wish to include the tube feeding details and progress, such as the diary that follows, with your folder or other items you take to your child's visits with their healthcare team.
- As your child gets older, help him or her to be more involved in their medical appointments or care for their tube feeding as much as possible.

## Other Resources:

This guide includes a wide range of information about tube feeding your child. We believe it is also helpful for you to have support from others who are caring for children who need tube feedings at home.

This website has been created by a group of parents who created a foundation in order to raise awareness and share their experiences with tube feeding their children:

Feeding Tube Awareness Foundation:

<http://www.feedingtubeawareness.com/index.html>

Nestlé Health Science also has a website to help you learn, share and discover with other parents of tube fed children:

ParENTalk™: <http://www.parentalk.com/Home/Index>



*"Our healthcare team has been very helpful, but I have really found that experience is the best teacher – it's the only way to learn! I did like being talked through it, but the only way I finally understood was to just do it over and over and over."*

—Joanne C., mom of Evelyn,  
age 5



*"The support we've received from other parents and organizations has been so helpful. I joined all kinds of forums to get as many ideas as I could. Sometimes you are just interested in support; sometimes you are really looking for information."*

—Jacquelyn F., mom of Rafael,  
age 6

# Keeping a **DIARY**

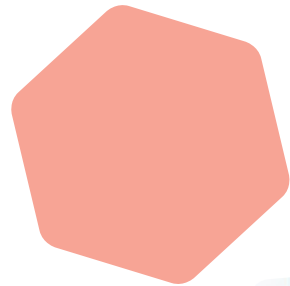
To help you and your healthcare professional keep track and assess your child's progress with your tube feedings, using a diary may help.

The diary shown on the next page is an example of how you can track their tube feeding progress over time. This can be very helpful if you are trying to make a change to the feeding plan and would like to measure how it is going.

When you visit your healthcare professional, take this diary to discuss during the visit.

Daily formula goal: \_\_\_\_\_ mL/containers

Daily water goal: \_\_\_\_\_ mL and/or \_\_\_\_\_ flushes



# DIARY

	Sun.	Mon.	Tues.	Wed.	Thur.	Fri.	Sat.
Date							
Weight							
Amount of Formula Taken							
Amount of Water Taken							
Other Fluid put Through the Tube							
Number of Stools/Diaper Changes							
Stool Consistency (hard, soft, watery)							
Tube Site (is skin clean, red or sore)							
Other							
<ul style="list-style-type: none"> <li>Intolerance symptoms and how often they occur</li> </ul>							
<ul style="list-style-type: none"> <li>Any questions or concerns related to the tube feeding</li> </ul>							

## Your Child's Tube Feeding **SCHEDULE**

<b>Your Child's Formula is</b>			
Total amount of formula each day _____		(number of containers of formula each day _____)	
Your child will use _____ cases of formula each month		Reorder your formula on the _____ day of each month	
<input type="checkbox"/> Feeding by Gravity or Syringe		<input type="checkbox"/> Feeding with a Pump	
Take your child feedings _____ times each day		Rate (mL/hour): _____	
If using gravity feeding, the formula flow rate will be _____ drips or _____ mL per _____ seconds		Hours to feed each day: _____	
Time	Amount	Feeding Time	
		From	To
		From	To
		From	To
		From	To
		From	To
		From	To
		From	To

<b>Water Flushes</b>
Before starting the feeding, flush your child's tube with _____ mL of water.
After the feeding is finished, flush your child's tube with _____ mL of water.
<b>OR</b>
Every _____ hours, flush with _____ mL of water.
<b>Notes</b>

## Your Child's Tube Feeding **SUPPLIES**

Have your healthcare professional fill in all of the sections below that apply



<b>Feeding Tube</b>	
Name/Type of Tube: _____	
Size of Feeding Tube (French size): _____	
Brand/Manufacturer: _____	
<b>Feeding Supplies</b>	
Feeding Formula: _____	Brand/Manufacturer: _____
Type of Feeding Container: _____	Brand/Manufacturer: _____
Change Feeding Container Every _____ (hours or days)	
Type of Tubing Needed to Attach to Feeding Container: _____	
Change Feeding Tubing Every _____ (hours or days)	
Name of Pump: _____	Brand/Manufacturer: _____
<b>Other Supplies Needed (such as syringes, tape)</b>	
_____	
_____	
_____	
_____	
_____	
_____	
_____	

## Contact **NAMES & NUMBERS**

If you have questions about your tube feeding the following people can help.

### Doctor:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Nurse:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Dietitian:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Formula Supplier:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Feeding Bags and Tubing Supplier:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Pump Supplier:

Phone \_\_\_\_\_

Email \_\_\_\_\_

## **OTHER CONTACTS:**

### Contact Name:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Contact Name:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Contact Name:

Phone \_\_\_\_\_

Email \_\_\_\_\_

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Phone \_\_\_\_\_

Email \_\_\_\_\_

### Contact Name:

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Contact Name:

Phone \_\_\_\_\_

Email \_\_\_\_\_





This booklet has been provided  
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professional as an educational  
service from Nestlé Health Science

Nestlé Health Science  
25 Sheppard Ave. West  
North York, ON  
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[www.nestlehealthscience.ca](http://www.nestlehealthscience.ca)  
or call 1-800-565-1871

