



A PRACTICAL GUIDE TO TUBE FEEDING

This guide has been provided to give you easy-to-follow explanations of the day-to-day aspects of tube feeding, as well as handy tips from other parents and caregivers. To begin with, all this information may seem overwhelming but with practice and support, all of these things will become second nature to you and your family.

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If the pump stops working or you have any questions please contact Nutricia Homeward:

**UK 0800 093 3672
NI 0800 169 5173
ROI 1800 221 800**

What's inside this guide?

Even once the decision has been made to go ahead with tube feeding for your child, you are still bound to have concerns and questions. Asking yourself questions such as 'what happens next?' and 'can I manage this?' is normal at this stage, as everything about this is new and not what you are used to.



Adjusting to life with a feeding tube may take a bit of time, and it's likely that more practical questions will arise as you and your child get into a routine. With the right information and support, over time you will become experienced in tube feeding your child, and begin to experience the many advantages that tube feeding brings.

Do not feel nervous about discussing any concerns and questions you have with the healthcare professional (HCP) involved in your child's care. There are also a number of specialist organisations and parent associations (details at the end of the guide) that can provide you with advice and support at this stage and in the future.

Many parents want to learn more at this stage, and express the need for more general tube feeding information and practical tips so that they feel more confident when handling their child's feeding tube.

"After we made the decision to get a feeding tube for Tom we then realised that we had no idea what we were doing. It felt scary, we had so many questions; how would we cope? How does it actually work?"

Choice of feeding tube

You will make the choice of feeding tube for your child after the discussion with your child's doctor/dietitian, taking into consideration his or her specific needs.

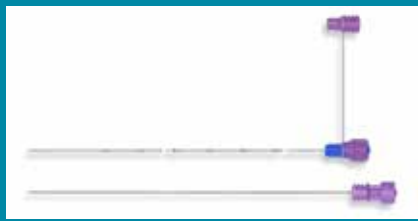
There are three types of feeding tubes, which are described below. Each of these feeding tubes differ slightly in terms of placement; however, their overall aim is the same; to provide your child with all the nutrients they need to help them grow, stay healthy and be happy, supporting them to get stronger to cope with their underlying conditions.

1. Nasogastric tube (NG tube)

This type of tube goes directly to the stomach, but the insertion point is through the nostril, not the stomach. It is typically considered for short term use (i.e. usually 6–8 weeks, although the time of tube feeding varies depending on the child's condition, and the consultant's advice).

For this type of feeding tube no surgery is required for its placement.

These type of tubes may accidentally move out of place; tube position needs to be checked before each feed. If the tube is needed for longer than 6-8 weeks a replacement tube is needed, a small dressing may be required on the nose or cheek.



2. Nasojejun tube (NJ tube)

These are less commonly used than other types of feeding tubes. They are also inserted through the nostril, but – unlike the NG tube – reach into the small intestine, not the stomach.

This type of feeding tube is suitable if a child is having problems with digestion or absorption.

These types of tubes always have to be replaced in the hospital. More easily dislodged, daily position check needed, short term tube replaced regularly, a small dressing may be required on the nose or cheek.



3. Gastrostomy tubes

A gastrostomy tube is placed directly into the stomach through an opening in the abdomen, known as a stoma, allowing enteral feed to be fed directly into the stomach. When a child needs a tube for a longer period of time, gastrostomy is in most situations recommended as the preferred option. Gastrostomy tubes include initial placement tubes and replacement tubes.

Initial placement tube:

Percutaneous endoscopic gastrostomy (PEG tube)

The tube is placed by means of an endoscope, typically under a general anesthetic in children. Once the stoma has healed, the tube can be replaced, if required, by a gastrostomy balloon replacement tube. This can take 12 weeks or more depending on waiting times.

Less visible than the NG tube and can last up to two years or as indicated by specific manufacturer's guidelines.

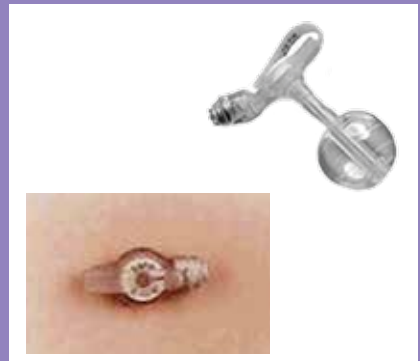
- Requires surgery for placement.
- Stoma infections can occur.

Replacement tube:

Gastrostomy balloon tube (G tube)

Low profile gastrostomy balloon tube (button)

This has a much shorter tube than the PEG tube and sits close to the skin. There are different types of buttons available, for example the MIC-KEY and the CuBBY button. This option is generally preferred by healthcare professionals and parents alike as it is more practical for use in children.



Your child's healthcare professional will provide advice on how to care for the tube.



Equipment you may need

Once, after discussion with your child's doctor/dietitian, it has been established what the best feeding tube is for your child, you are probably asking yourself certain questions about what happens next:

Additional equipment required to start tube feeding

- Pump
- Giving set
- Extension set (only applicable when button devices placed)
- Syringe

Type of feed*

- Ready to feed nutrition, i.e. tube feeds only
- A combination of oral feed and ready to feed nutrition, i.e. tube feed

Feeding routine*

- How do I give my child a feed through the tube?
 - Pump method
 - Gravity/bolus method
- Feeding regimen
 - Continuous feeding
 - Overnight feeding
 - Bolus feeding

** Type of feeds and feeding routines should be decided by the dietitian or doctor in partnership with the parents/carers.*

EQUIPMENT THAT MAY BE REQUIRED TO START TUBE FEEDING

The feeding tube that has been selected for your child comes as part of a package of equipment designed to make feeding your child as straightforward as possible. All of the additional equipment you need to start tube feeding at home will be given to you by your child's care team, who will also explain to you how to use it.

The kit includes:



A **pump** to deliver the feed through the giving set at a controlled rate set by you.



A plastic **extension tube** that attaches the giving set to the gastrostomy tube (needed only if low profile/button is in place).



A **feeding tube** may have two ports; one for balloon inflation with water (luer slip syringe required), and one for feed administration. However, a lot of PEGs and extension sets will only have a male luer port.



A **giving set** – a plastic tube attached to the bag containing the feed at one end and the feeding tube or extension set at the other with the feeding pump in the middle to deliver feed at a set rate and volume.



Syringes* to administer feed, water, medication, or aspirate (remove liquid from the feeding tube). Syringes come in different types and different sizes (e.g. 10 or 60 ml).

* Syringes used for balloon checks are different to enteral flushing and feeding syringes.

TYPES OF TUBE FEEDING

When it comes to deciding what to put into the tube, your child's dietitian or doctor will work with you to find what type of feed is best. The choice will depend on your child's nutritional needs, age, growth rate and any allergies for example.

Ready to feed nutrition

Most dietitians/doctors recommend the use of ready to feed nutrition. Its advantages are that it is:

- Specifically made for children who need a feeding tube
- Specifically designed to meet children's nutritional requirements
- Sterile
- Convenient
- Flows easily through the feeding tube so less risk of blockages
- Can be used alone or in combination with oral feeding



Combination feeding

If your child's doctor/speech and language therapist agrees, and your child can still consume food orally, you may prefer to combine feeding him or her by mouth in addition to tube feeding.

Always discuss the possibilities with your healthcare professional before commencing combination feeding.

Some children like to eat normally during the day and are tube fed only at night, others are tube fed only after meals if they cannot eat enough food by mouth. In some cases, children may not want to eat by mouth at all, and there are a few reasons why children are reluctant with oral intake – this can be because they associate it with feeling ill or their doctor has recommended them not to.

“We like to eat together as a family around the table; it means we can continue to share special family moments as we always have and it encourages Sarah to try different foods.”

“After Thomas' tube was fitted, our speech and language therapist said it was important for him to keep eating by mouth to develop the muscles he uses for chewing, swallowing and speech.”

Did you know?

If needed the tube can also be used to administer medication. This can be an important benefit if your child has difficulties swallowing or dislikes the taste of the medicine. Your pharmacist will be able to give you advice on when your child's medication should be taken (e.g. on an empty or a full stomach), and how best to administer different forms of medication (i.e. liquids, tablets, or capsules) through the tube.

FEEDING ROUTINE*

How do I put the feed in the tube?

Getting feed into the tube can be achieved using a pump or syringe. With the pump, you can programme the rate at which the feed flows through the tube so that you know exactly how much feed your child has been given. Your choice of pump will depend on your circumstances and your child's needs. Specific details on how to use different types of pump are provided by your pump supplier.

Gravity feeding is the method of feeding using an open syringe/bolus where you slowly pour an enteral feed into the syringe or an extension set. The speed of delivery can be varied depending on the height of the syringe. If required, your dietitian/doctor will be able to provide more information on the differences between these feeding methods. In some cases a syringe can be used with a plunger to administer the feed.

For how long should I feed my child?

Depending on your child's nutritional requirements, medical needs and his/her preferences, your child's doctor or dietitian may recommend either continuous or bolus feeding.



With continuous feeding, the feed is given slowly over a number of hours using a pump (see below). It is possible for this to happen overnight whilst your child is sleeping.

Bolus/portion feeding is when feed is given by pump or syringe over short periods of time several times a day.

Visit www.nutriciaflocare.com to learn more about pumps, feeding tubes and giving sets. The website also gives access to interactive training tools, such as an online pump simulator.

* Feeding routines should be decided by the dietitian or doctor in partnership with the parents/carers.

JACK'S STORY

"I start Jack's feeding by pouring his feed into the feeding container, hang the feed container up and let some of the feed run down the tube to let any air out.

I then flush his feeding tube using room temperature water to make sure it is clean and any blockages are removed.

When we are ready to feed, I attach the tube on the end of the feeding bag to Jack's feeding tube and turn on the pump. I set the rate according to Jack's feeding plan and press start.

Once feeding time is over, I stop the pump, separate the tube from his feeding tube and flush again as before.

Normally we then sit together and talk or read a book for an hour or so to let his food go down.

I like to make sure that all the equipment is cleaned and put away so that it's ready to go for his next feed that day."



POTENTIAL COMPLICATIONS

No matter how experienced you are, occasionally things can go wrong and accidents may happen when tube feeding your child.

If you are in any doubt as to what to do when tube feeding your child, or if any problems arise, there are always places where you can seek help.

- If the pump stops working please contact Nutricia Homeward on 0800 093 3672
- You should contact your local hospital if, for example:
 - The feeding tube comes out
 - The tube is still blocked
 - Your child is unwell (diarrhoea, constipation, upset stomach, etc)
 - Your child has pain on feeding. In this instance please stop feeding
- If your child has redness, swelling or discharge around the tube site, please contact your doctor immediately.



Daily life

TUBE FEEDING EXPERIENCES

Pulling the tube out: *“When Anna was first fitted with her tube, I was really worried about her pulling at it and it coming out. I was told by another parent to use a doll and put tubing on it – the same as Anna’s. We then explained to Anna using the doll what she can and cannot touch, and what she needs to be careful with. This really worked for us; she loves her doll so she follows exactly what she does. We were also told that using mittens was a good way to keep little fingers out but we didn’t need to do this in the end.”*

Playing outdoors: *“With my child, when he is playing in the park for example, we tuck any extra tubing into his clothes. When he was younger we used all-in-one clothes so that he could go wherever he liked and not have to worry about knocking his tube. A lady I know from the parents association has a boy with an NG-tube. She tapes a little bit of excess tubing to his face. It is only temporary but it means that if it gets caught she knows about it before it comes out.”*

Swimming: *“Our doctor told us that we could start swimming 6–8 weeks after the button was fitted. We had no problems; we had to make sure that we kept the tube closed before getting in the water, but other than that it was like it always has been. It’s the best part of his day.”*

Holidays: *“For us it really depends on how long we go for. Short weekend breaks are easy to do. We take an extra tube just in case it needs replacing, his feed and one set of equipment. I have a checklist so I knew exactly what to take. To hang the feed I just used a hanger or hook rather than taking the Z frame stand with me. Long trips take a bit more planning but we love travelling, we flew to Australia last year with no problems, we just had to keep in mind where to go if there were any problems but this never happened.”*

AT A GLANCE CHECKLISTS



Use the following checklist as a reminder before and during feeding time. Additional information is available on tube care from your healthcare professional.

Things to check at feeding time

- Check the label of the tube feed to make sure it is the correct tube feed for your child and that it is in date.
- Follow the hygiene rules as outlined on the label of the tube feed.
- Check that the feeding tube is in the right position before feeding (your child's care team will show you how to do this).
- Flush the tube through before and after adding the feed (or medication) to avoid blockages, or follow the instructions provided by your dietitian/doctor.
- It is important to position your child in an upright position whilst feeding and for one hour after feeding as advised by your nurse.

Things to check every day

- Clean around the insertion site for the feeding tube every day.
- Look after the skin around the tube to avoid irritation (your child's care team will advise you about what this entails).
- Make sure your child stays hydrated by giving them water through the tube, or orally if safe. Speak to your dietitian to discuss how much water you can use.
- Keep your child's teeth and gums healthy by cleaning their teeth twice a day even if they are not feeding or drinking through their mouth.

In the beginning, it may seem that there is lot to remember, but with time all of these things will become second nature to you, and you and your child will be able to enjoy feeding time.

AWAY FROM HOME



Use this checklist if you want or need to travel away from home, either for a special occasion, holiday or to visit the hospital for a check-up or test, to ensure that you have everything you need.

- Tube feeds
- Medication, if applicable
- Water for flushing
- Syringes
- Feed container
- Extension tube and clamp if needed
- Feeding pump (if needed) and pump charger
- Spare giving sets and replacement feeding tubes, syringes and sterile water, if you are comfortable doing this yourself
- Towels, wipes, tape
- Soap for skin care
- A way to hang the feeding bag while away from home (usually in a carry system)
- Plastic containers/bags to store feeding supplies
- Phone numbers for the healthcare provider
- Your child's care plan (see next page)
- This booklet

Nutricia Homeward Holiday Service

At least six weeks in advance of a holiday abroad, contact Nutricia Homeward for information on the Holiday Service

YOUR CHILD'S CARE PLAN

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This page is designed for you to fill in and refer to, or to give to a caregiver, for example, so that they have all the information they need to feed your child for the day.



Type of tube _____

Size of tube _____

Date placed _____

Feeding method _____

Feeding time _____

• Feed name _____

• Amount of feed per day:

The flow rate set on the pump for your child is _____ mls/hour

The dose or volume on the pump for your child is _____ mls/hour

Flushing

• Amount before and after feeding _____ mls

• Amount during continuous feeding (every ____ hours) _____ mls

• Amount before and after medication _____ mls

Doctor's name and number _____

Dietitian's name and number _____

Patients & carers helpline _____

In case of an emergency, ring _____

Frequently asked questions

Do I need to keep the feed refrigerated?

Store unopened feed at room temperature (between 5–25°C) in a cool, dry place. You do not need to keep unopened feed in the fridge. Once opened, feed can be kept for a maximum of 24 hours.

The nasogastric tube has been accidentally removed or has changed position. What should I do?

If the tube has been accidentally removed or changed position it is important to contact a healthcare professional for advice — it is important that the tube is not used until it has been confirmed that the tube is in the correct position — the stomach. Otherwise contact the Nutricia Homeward Enteral Nurse Specialist, district nurse or GP. They will arrange to have another tube inserted. Always re-check its position before starting feeding.

My child's PEG tube has accidentally been removed. What do I do?

Place a dressing over the site and go to hospital immediately for reinsertion of the tube. A replacement tube should be inserted as quickly as possible. Contact the hospital beforehand to avoid waiting in Accident & Emergency.

What should I do with giving sets and reservoirs after I have used them?

You can dispose of giving sets, reservoirs, containers, bolus adapters, 2-pack connectors and used feed packs with household waste.

If my child needs to take a break during feeding what should I do?

If your child is taking a short break that is less than an hour, you should:

- Disconnect the tube from the giving set;
- Replace the end cap on the giving set; and
- Flush the feeding tube.

If your child is having a longer break of more than one hour you should do as above and then put the feed into the fridge, leaving the giving set attached to the feed. When you take the feed out of the fridge, leave the feed at room temperature for 30 minutes before you start feeding again.

FREQUENTLY ASKED QUESTIONS CONTINUED

Can my child have baths, showers or swim?

Yes, once the stoma tract has been fully formed after they have had the PEG or JEJ tube in place your child can bath, shower or swim as normal. When your child is allowed to take baths and swim, make sure that the tube is closed before immersing it in water. Be sure that you dry the area thoroughly afterwards.

NOTE: The PEG Clinical Nurse will advise you on exactly when your child can bathe.

Will my child need the tube forever?

Some children need tube feeding for short periods of time, while others may need them long term. Your child's doctor/dietitian will discuss the expected length of time your child will require a feeding tube. Your child's progress will be reviewed regularly by their consultant and dietitian.

Can my child eat normal foods while being tube fed?

You will be informed by your doctor/dietitian if your child can eat while on tube feeds. If they are allowed to eat, you will be given information about what types of food and amounts your child can eat. If your child has swallowing difficulties a speech & language therapist will assess your child's swallow and will advise you if it is safe for your child to eat by mouth.

I no longer require the feeding pump. What should I do?

It is important to return the pump to Nutricia Homeward when you have finished using it.

You can arrange to return the pump by contacting Nutricia Homeward on 0800 093 3672.

We will arrange to collect all the equipment and we will pay any charges related to the return of equipment.

INFORMATION, ADVICE AND SUPPORT ABOUT TUBE FEEDING

www.pinnt.com

www.nutricia.co.uk

www.tubefeeding.co.uk

For more information please contact your healthcare professional.

READING MATERIALS

The following are additional sources of information about tube feeding which you may find helpful:

How do you feel about tube feeding

Practical advice on the signs that may indicate that your child requires a tube feed.



Making the decision to start tube feeding

For information about the range of tube feeding products available.



To request a copy of these booklets please contact the Nutricia Resource Centre on **0333 577 7826** or resourcecentre@nutricia.com.

GLOSSARY OF TERMS

Bolus feeding	The feed is given in smaller volumes (e.g. 200ml) one at a time, several times throughout the day (e.g. up to 7 feeds) with the use of a pump, gravity or a syringe
Button	A low profile gastrostomy it is skin level, and is retained by a small balloon inside the stomach
Clamp	A small device on the feeding tube which, when pressed closed, prevents leakage from the feeding tube
Continuous feeding	The feed (e.g. 1000ml or 1500ml) is given slowly over a number of hours using a pump that controls the flow rate of the feed
Endoscope	A slender tube used to examine the inner part of the body with an attached instrument for biopsy or surgery
Enteral feeding	Feed that passes directly into the stomach or intestine
Extension set	A tube that can be attached between the giving set and the feeding tube
Flushes	Water given via the tube to avoid any tube blockage and maintain hydration
Gastric	Anything related to the stomach
Gastrostomy	An opening through the abdominal wall into the stomach
Gastrostomy tube, G tube	A feeding device through which enteral feed, fluids and/or medication can be given. A G tube is placed directly into the stomach through an opening in the abdominal wall (stoma) and has a small balloon end present to hold the button in place
Giving set	A flexible tube that helps to deliver the feed. It is attached to the tube feed bag at one end, and the feeding tube with the pump in the middle
Gravity feeding	Feeding that enters the stomach by gravity (i.e. placing the feed above the height of the stomach)

Nasogastric tube, NG tube	A nasogastric tube is designed for tube feeding and placed through the nose, down the oesophagus and into the stomach. The position of the NG tube must be confirmed before each feed can commence
Oesophagus	Often called food pipe, it is a part of the gastrointestinal system where food and drink are moved from the mouth to the stomach
Oral	Anything related to the mouth
Overnight feeding	Feed that is typically given during night-time, often through a feeding pump
Pump	A device that delivers feed through a tube at a set rate & volume
Pump feeding	Feeding that is given using a pump
Stoma site	An opening from the outside of the body through the skin where the feeding tube enters into the stomach or the small intestine (jejunum)
Syringe	A medical device designed to administer fluid, feed or medications, or remove fluid
Trachea	The 'wind-pipe' that carries air from the mouth to the lungs
Tube feed, formula	Specifically formulated enteral nutrition products designed to meet the patient's specific needs
Tube feeding	A way of getting your body the nutrition it needs. Tube feed is a liquid form of nourishment that's delivered to your body (stomach or small intestine) through a flexible tube
NJ tube	A nasojejunal tube is designed for tube feeding, usually placed in hospital and can't be replaced in the community. The tube is placed through the nose, down the oesophagus, through the stomach and into the small intestine (jejunum)
PEG	A Percutaneous Endoscopic Gastrostomy tube is a gastrostomy tube inserted using an endoscope. The tube has an internal retention disc inside the stomach to prevent it from falling out

We warmly thank all parents and children who contributed to this guide.

If the pump stops working or you have any questions please contact Nutricia Homeward:

UK 0800 093 3672

NI 0800 169 5173

ROI 1800 221 800

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