



ADVICE

SHARING THE CARE  
FOR GOOD NUTRITION

# A practical guide to tube feeding

# What's inside this guide?

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**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.**

*“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?”*



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 health care professionals (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.

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.

**Topics covered in this brochure:**

## Choice of feeding tube

- Gastrostomy tube: initial placement (PEG)
- Nasogastric tube (NG tube)
- Nasojejunal tube (NJ)

## Next steps

- Feeding equipment
- What to feed
- Different feeding methods
- Step-by-step feeding from a parent's perspective

## Daily life

- At-a-glance checklists
- Your child's care plan

## Glossary of terms

## Where to look for more information

# Choice of feeding tube



## Choice of feeding tube

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

There are three types of feeding tube, which are described below. Each of these feeding tubes differs 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 nose, not the stomach. It is typically considered as a short term (i.e. usually 6-8 weeks, although the time of tube feeding varies depending on the child's condition, and the consultant's advice).

**Advantage:** for this type of feeding tube no surgery is required for placement.

**Disadvantages:** more easily dislodged, daily position check needed, short term tube replaced regularly, may be small dressings on 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 nose, but - unlike the NG-tube - reach into the small intestine, not the stomach.

**Advantage:** this type of feeding tube is suitable if a child is having digestive problems related to the stomach for example.

**Disadvantages:** these types of tubes always have to be replaced in the hospital. More easily dislodged, daily position check needed, short term tube replaced regularly, may be small dressings on 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 digestive system. 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.

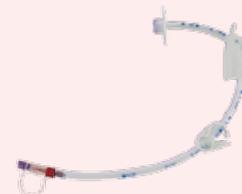
### Initial placement tube

#### Percutaneous endoscopic gastrostomy (PEG tube)

The tube is placed by means of an endoscope, typically under a general anesthetic in children. Once the stoma channel 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.

**Advantage:** less visible than the NG-tube and can last up to 2 years.

**Disadvantages:** requires surgery for placement; stoma infections can occur.



### Replacement tube

#### Gastrostomy balloon tube (G-tube) or 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 health care professionals and parents alike as it is more practical for use in children.





# Next steps

**Once 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
- Feeding set
- Extension set  
(only applicable when button devices placed)
- Syringe

## Choice 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 method
- For how long should I feed my child?
  - Continuous feeding
  - Overnight feeding
  - Bolus feeding

\*Feeding routine should be decided by the dietitian in partnership with the parents/carers.

## Additional equipment 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 that 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 feeding set at a controlled rate set by you.



A plastic **extension tube** that attaches the feeding set to the gastrostomy tube (needed only if low profile is in situ).



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.



**Syringes\*** to administer or aspirate (remove) liquid from the feeding tube. Syringes come in different types and different sizes (e.g. 10 or 60 ml). You can also administer medication by syringe if necessary.

**Please note** that male oral and male luer syringes will not fit the end of PEGs/extension sets/NGTs or NJTs, as these are female luer.



A **feeding 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 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
- Nutritionally complete and balanced
- 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 dietitian or doctor agrees – and if your child wants it – you may prefer to combine feeding him or her by mouth with tube 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 alone. 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?

In some cases you might be able to administer medication through the feeding tube. 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 about 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 gravity.

With the pump, you can programme the rate at which 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.

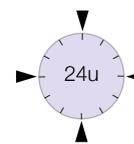
Gravity feeding is the method of feeding using an open syringe where you pour feed into the syringe over a period of 15-20 mins. The speed of feed delivery can be varied depending on the height.

### For how long should I feed my child?

In addition to helping you to decide which type of tube and which type of feed is best for your child, his/her dietitian/doctor will also discuss with you the most suitable method, by which to feed your child. As before, this will take into account your child's preferences as well as his or her medical needs. The dietitian/doctor may suggest either **continuous** or **gravity/bolus** feeding or even a combination of the two.



**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](http://www.nutriciaflocare.com) to find out more about the different Nutricia pumps available (e.g. the Infinity and Infinity+ pump) and related interactive training tools.

## 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 your Nutricia Homeward Patient Coordinator or the out of Out of Hours Advice Line 08457 623636.
- 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.

**Please note** that the feeding plan discussed with your dietitian/doctor is specific to your child.



### *Jack's story*

*"I start Jack's feeding time 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."*



## 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.

### Things to check at feeding time

- Check type of tube feed to make sure it is the correct tube feed for your child.
- Follow the hygiene rules provided to you by your child's caregiver.
- 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.
- Position your child in an upright position when feeding during the day, or with their head raised in bed if feeding overnight.

### Things to check everyday

- 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 that your child stays hydrated by giving them water through the tube (speak to your dietitian to discuss how much water you can use) or orally if safe, appropriate and agreed with healthcare team.
- 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 mouths.

In the beginning, it may seem that there is a 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.

- Feed
- Medication
- Water for flushing
- Syringes
- Feed container
- Extension tube and clamp if needed
- Feeding pump (if needed) and pump charger
- Spare feeding 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 health caregivers
- Your child's care plan (see next page)
- This booklet



# Your child's care plan

CHILD'S PHOTO

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  
.....
- Tube information  
.....
- 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 x hours) ..... mls
  - Amount before and after medication ..... mls
- Doctor's name and number  
.....
- Patients & carers helpline  
.....
- In case of an emergency, ring  
.....

# Information, advice and support about tube feeding

[www.pinnt.com](http://www.pinnt.com)  
[www.nutricia.co.uk](http://www.nutricia.co.uk)  
[www.tubefeeding.co.uk](http://www.tubefeeding.co.uk)

For more information please contact your **Health Care 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 is ready to tube feed.



### Making the decision to start tube feeding

For information about the range of tube feeding products available.



## Glossary of terms

<b>Bolus feeding</b>	A feed that is volume-dependant given over a short period of time
<b>Clamp</b>	A small device which when pressed closed prevents leakage from the feeding tube
<b>Continuous feeding</b>	A feed that is given at a pre-set rate, continuously for many hours via pump
<b>Endoscope</b>	A thin and flexible tube that is passed through the mouth, and down towards the stomach (for investigation and tube placement)
<b>Enteral feeding</b>	Feed that passes directly into the stomach or intestine
<b>Extension set</b>	Plastic tubing which can be attached between the feeding set and the feeding tube
<b>Feeding set</b>	A plastic tube that is attached to the bag with the feed on one end and the tube or extension set on the other
<b>Flush</b>	Water given to clear the feeding tube/extension tube
<b>Gastric</b>	Anything related to the stomach
<b>Gastrostomy</b>	An opening through the abdominal wall into the gastric cavity
<b>Gastrostomy tube, G-tube</b>	Feeding device through which formula, 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 balloon end present to hold the button in place
<b>Gravity feeding</b>	Feeding that enters the stomach by gravity (i.e. placing the feed above the height of the stomach)
<b>Nasogastric tube, NG-tube</b>	A feeding device through which enteral feed, fluids and/or medication can be given directly into the stomach. An NG-tube is inserted through the nose, passed down the oesophagus and enters directly into the stomach
<b>Oesophagus</b>	Referred to as the 'swallowing' tube – the path through which food and drink are moved from the mouth to the stomach
<b>Oral</b>	Anything related to the mouth
<b>Overnight feeding</b>	Feed that is typically given during night-time, often by pump
<b>Pump</b>	A device that delivers feed through the tube at a rate set by you and volume
<b>Pump feeding</b>	Feeding that is given using a pump
<b>Stoma</b>	A surgical opening in the abdomen
<b>Syringe</b>	A medical device used to administer or remove fluid
<b>Trachea</b>	The 'wind-pipe' that carries air from the mouth to the lungs
<b>Tube feed, formula</b>	Specifically formulated liquid nutrition that can be tailored to individual needs
<b>Tube feeding</b>	Supplemental nutrition through a special tube that enters directly into the stomach or intestine
<b>NJ</b>	An NJ tube is placed usually in hospital and can't be replaced in community. The tube is passed through the nose down the oesophagus and into the small bowel
<b>Button</b>	A low profile gastrostomy it is skin level, and is retained by a small balloon inside the stomach. These devices are usually changed every 3-6 months at home by a healthcare professional or yourselves if this is something that you want to learn to do
<b>PEG</b>	A Percutaneous Endoscopic Gastrostomy tube which is placed under general anaesthetic there is a bumper inside to prevent it from coming out. The tube outside the body is approx 20-25cm long

## Your notes...

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## We warmly thank all parents and children who contributed to the elaboration of this guide.

This guide is available free of charge from Nutricia Advanced Medical Nutrition.

### Carers UK

20 Great Dover Street, London SE1 4LX

Visit:  
[carersuk.org](http://carersuk.org)

### Carers NI

58 Howard Street, Belfast BT1 6PJ

Visit:  
[carersni.org](http://carersni.org)

### Carers Scotland

The Cottage  
21 Pearce Street,  
Glasgow G51 3UT

Visit:  
[carersscotland.org](http://carersscotland.org)

### Carers Wales

River House  
Ynys Bridge Court,  
Cardiff CF15 9SS

Visit:  
[carerswales.org](http://carerswales.org)

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