

Gastrostomy tubes

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Why does my child need a gastrostomy?

If your doctor feels it is advisable for your child to be fed through a tube, either as well as or instead of feeding by mouth, he/she will discuss this in detail with you.

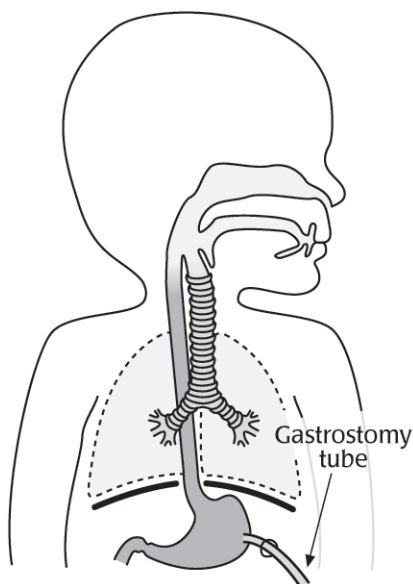
However, there are two main reasons why a TOF child may need a gastrostomy:

- if a child is not managing to swallow enough for him/her to grow properly, a gastrostomy may be fitted, to meet the child's nutritional needs.
- if your child's oesophageal atresia has not been 'joined up' so that he/she cannot swallow at all, then a gastrostomy will be required.

What is a gastrostomy?

A gastrostomy tube is a specially designed tube through which your baby/child can be fed. It is inserted through the skin directly into the stomach. Your child/baby will need a general anaesthetic for this procedure. The doctor will explain the operation to you, but it is important that you ask questions if you feel unsure about any aspect of the procedure, so that you fully understand what is involved.

The tube stays in place until it needs replacing or the child is eating enough that a gastrostomy is no longer required.



What is a stoma ?

The stoma is the surgical opening in the abdominal wall through which the gastrostomy tube is inserted. The stoma is red and the size of a very small sultana.

What sort of gastrostomy tube will my child have?

There are a variety of gastrostomy tubes and skin-level devices (called 'buttons') in use. The most appropriate tube will be chosen by the doctor after talking with you.

All tubes are all made from a soft material called silicone. Nursing staff will show you the ones available and how they are cared for. If you think it may be helpful to see the device or meet someone who experience of a gastrostomy, ask the medical staff.

Tubes can be split into three categories:

S u r g i c a l l y
This kind of tube is put in during an operation under general anaesthetic. At one end it has a balloon or cross bar which sits inside the stomach and helps to stop the tube falling out; the other end of the tube may have one or more openings which are used to care for the tube.

This type of tube is for short term use and is usually changed easily by the medical staff. The length of time the tube can stay in place will be discussed with you.

P e r c u t a n e o u s
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This type of tube is also placed during an operation under a general anaesthetic, however a flexible telescopic endoscope is used to help position the tube. It will have a disc or cross bar to help prevent it accidentally coming out.

These tubes are more suited to long term usage and can stay in place for many months. At the moment, their design requires them to be removed endoscopically, with the child under a general anaesthetic, when they first need to be changed.

There are a small number of patients who are not able to undergo this procedure and will require a surgically placed tube.

This information has been written for the parents of TOF children by TOFS (Tracheo-Oesophageal Fistula Support) – helping children born unable to swallow.

If you have any feedback on this leaflet, please use our leaflets feedback form which is available from either the TOFS office or our web site.

TOFS relies on money from membership fees, voluntary donations and other sources of charitable income to fund its activities.

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offering emotional and practical support to meet the needs of parents and providing a source of information which complements that given by the specialist hospital.

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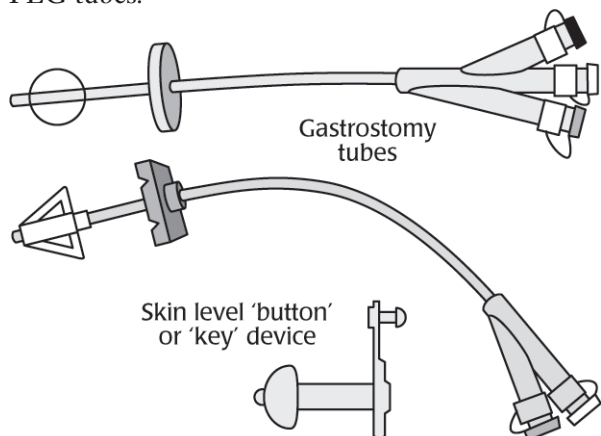
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S k i n

These are much shorter than the other types of gastrostomy tube and sit flush with the skin. They have a balloon or mushroom-shaped end which sits inside the stomach. This prevents it from falling out. With proper care, they can stay in place for many months and are sometimes used to replace surgical or PEG tubes.



How do I feed my child?

Feeds which are put through a gastrostomy tube are special formulations which will initially be provided by the dietician and then prescribed by your GP.

The dietician will start your child with small, frequent amounts of feed. The volume of the feed will then be increased as your child gets used to it. If your baby's/child's stomach is too full, feed may leak around the stoma site.

Your dietician will discuss the best way to feed your child with you, and you should be fully confident about feeding on your own by the time you leave the hospital. Some feeds are administered overnight, using a special pump, while others are given by bolus ('in one go'):

B o l u s

Feed is given at regular times using a gravity feed pack which consists of a syringe or funnel to which tubing is connected. The tubing is attached to your baby's/child's gastrostomy tube. The feed is then allowed to go into the stomach over 15-20 minutes.

C o n t i n u o u s

A computerised pump is used to deliver the feed slowly over many hours; nursing staff will teach you how to use the pump.

How should I position my child when giving a feed?

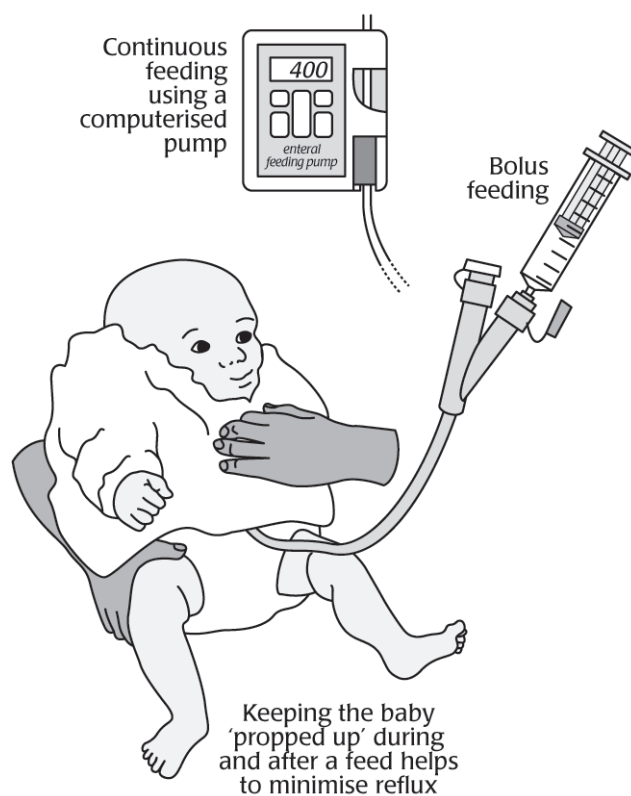
Try and make him/her as comfortable as possible. The best feeding position is sitting or 'propped up' because this helps the food to move through the stomach to the intestines and minimises reflux.

Is there anything I can do while my child is having a feed?

It is important that your child has the chance to be with the family at mealtimes; mealtimes are social occasions and your child should be included. You should encourage your child to touch and taste food just like other children.

Children who have been fed by gastrostomy for a long time may develop to be poor feeders, so it's important to make their gastrostomy feeding experience as close as possible to a 'normal' mealtime so that the transition to oral feeds is as stress-free as possible:

- Let your child have something in the mouth to taste while they are being gastrostomy fed. This will enable them to associate the sight, taste and smell of food with the feeling of hunger being satisfied.
- Encourage your child to play with foods.
- Talk to your child at mealtimes.
- Offer plenty of praise and encouragement when small amounts of food are put in the mouth.
- Between meals, when your child is in the mood, encourage mouth games using the mouth and tongue e.g. blowing and kissing. This will get him/her used to having things in and around the mouth and will help them later with normal feeding. If he/she does not seem able to move food around the mouth and swallow properly, inform the doctor.



What else do I need to know?

It is important that the dietician, nurses and doctors are aware of any problems you experience.

Always supervise your child's feeding, and do not leave him/her unattended.

Your baby/child may be prone to 'wind' or colic. You will be shown how to prevent this by opening the end of the tube before feeding and allowing the air to come out – so 'venting' the tube.

Other aspects of routine care include keeping the site clean, flushing it to prevent it getting blocked, and checking that it is in the correct place before feeding. It is also important to ensure that the tube is not left to dangle in the child's nappy/pants area for hygiene reasons.

You will need to know what to do if the tube does become blocked.

If your child becomes distressed during feeding, experiences nausea, diarrhoea or starts to vomit, or if the stoma site becomes reddened, you must contact the hospital for advice.

What about bathing or swimming with a tube?

Some types of gastrostomy tube are more flexible than others in usage, but it is possible to allow these activities for most children with a few preliminary precautions. Ask nursing staff for advice.

What happens if the tube falls out?

Some types of gastrostomy are more likely to fall out or be pulled out than others, but whatever type of tube your child has fitted it's as well to be prepared for this possibility in case it happens.

First, cover the stoma with a clean towel to catch any leakage and keep the site clean.

After this, it is important to get the tube replaced as quickly as possible. If the stoma is left for as little as a few hours with nothing keeping it open, it will close up – and if left for too long, then a general anaesthetic may be required to re-open the stoma and place the new gastrostomy tube.

Some parents may be taught how to replace their child's gastrostomy, depending on the individual hospital and the type of tube in use. If you have been shown how to do this, and are confident about your ability, then replace the tube without delay. Do not attempt to replace the tube unless you have been taught how to do so.

If you need help, then it is important to get to the hospital which originally put the gastrostomy in, or to the local accident and emergency (A&E) unit, without delay. Call your surgical unit for advice. If you are some hours from them, the local hospital may be able to put something into the stoma to keep it open and tape this in place so that you can then travel to your surgical unit for proper tube replacement. Unfortunately some local A&E centres may not see this as an urgent situation, but if you explain what you require this will help to achieve the desired result.

Lastly...

Having a child with a gastrostomy will involve you some extra work and will inevitably be quite stressful at first, until you get used to the routines involved.

Try not to let feeding dominate your life – accept what help you are offered from friends and family, and remember that the hospital staff are there to answer queries and offer support when you need it.

Related leaflets from TOFS which you might like to read:

- 1 Nasogastric tubes
- 2 Jejunostomy tubes
- 3 Gastro-oesophageal reflux
- 4 Long-gap OA - delayed anastomosis
- 5 Long-gap OA - oesophageal substitution

These are all available from the TOFS web site (www.tofs.org.uk) or from TOFS office.

TOFS also publishes a book, 'The TOF Child,' which is suitable for both parents and medical professionals. Details are available from TOFS.