

Living with a gastrostomy feeding device

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This information sheet explains about gastrostomies, how they are inserted at Great Ormond Street Hospital (GOSH) and how you will need to look after it once you return home.

Your child's device	
Size	
Date inserted	

GOSH switchboard	020 7405 9200
Gastrostomy Service	Ext 5695 or bleep 0321

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What is a gastrostomy?

A gastrostomy is a surgical opening through the abdomen into the stomach. A feeding device is inserted through this opening.

This allows your child to be fed directly into their stomach, bypassing the mouth and throat.

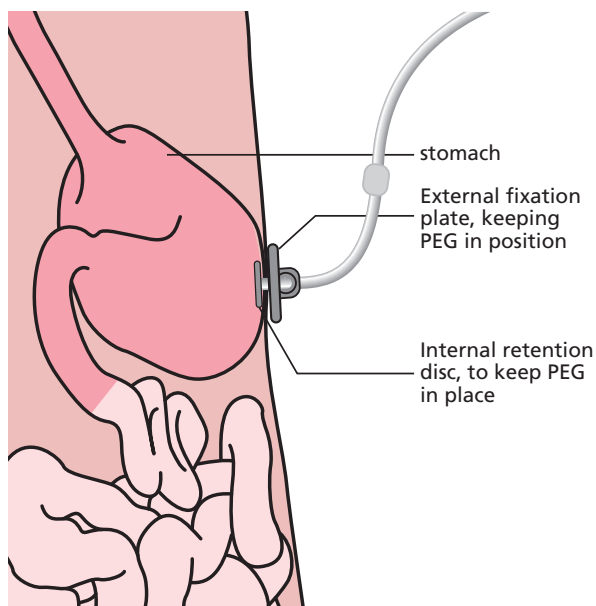
Why might my child need one?

People who have difficulties feeding can benefit from a gastrostomy.

There are many reasons why someone might have feeding

difficulties, including neurological (nervous system) disorders and gastrointestinal (digestive system) disorders. Some people also have difficulty swallowing, which increases the chance that they will breathe in food (aspirate).

A number of children will have been feeding using a naso-gastric tube (a thin, plastic tube that is inserted into one of the nostrils, down the back of the throat into the stomach) for some time and decide that a longer term device such as a gastrostomy is needed. Your doctor will explain to you the specific reasons why your child needs a gastrostomy.



Gastrostomy feeding devices

One type of gastrostomy device used at GOSH is a Freka® PEG, which consists of a flexible polyurethane tube held in place by a disk inside the stomach. An external triangle fixator sits on the skin of the abdomen and keeps the tube securely in position.



carried out by a surgeon in the operating theatre. It is held in place using wide, flat wings inside the stomach and will be temporarily stitched to the skin.



They stay in place for six weeks before being changed to a balloon device.

Other types of device used at GOSH include a Malecot® tube or balloon device (button or tube).

Malecot® tubes are temporary devices inserted directly into the stomach using an open or laparoscopic incision through the abdominal wall under general anaesthesia. The procedure is

Balloon devices (buttons or tubes) are usually inserted as a second device after the gastrostomy tract is established, following previous insertion of a Malecot® tube or a Freka® PEG. Please see the later section on second devices for further information.

Moving on to a second device

The initial PEG can stay in place for 18 months to two years, but will need to be replaced at this point, as the plastic tubing becomes worn. It needs to stay in place for a minimum of six months. Please contact us nearer the time to discuss the device change further.

When the time comes to change the device, you will have the choice of having the tube replaced with another of the same type or switching to a balloon device (pictured below). The balloon device is held in place inside the stomach wall using an inflatable balloon and connector sets are used to give feeds.



Balloon device

How is a gastrostomy device inserted?

There are several methods of inserting a gastrostomy feeding device used at GOSH: endoscopically, radiologically and surgically.

A number of children have a gastrostomy inserted during another operation, most commonly fundoplication to reduce gastro-oesophageal reflux.

The method chosen to insert a gastrostomy device depends on many factors, including your child's weight, medical condition, and previous or planned abdominal surgery. Your child's doctor will explain why a particular method has been chosen as best for your child.



PEG device

Endoscopically

This procedure uses an endoscope (flexible plastic tube with a camera and light at the end) to insert the gastrostomy device. It is carried out by a surgeon in the operating theatre or a gastroenterologist in the gastroenterology investigation suite.

Once your child is asleep, their abdomen will be cleaned with antiseptic solution. The doctor will pass the endoscope down through your child's mouth into the stomach and inflate the stomach with air. This air makes the stomach easier to reach from the skin.

The light at the end of the endoscope will be visible through your child's skin and shows where to make a small incision. A needle is then passed into the stomach and a long string is fed through the needle. This is then grasped by the endoscope and the end brought out of your child's mouth.

The gastrostomy device will then be passed down through your child's mouth into the stomach using the guide string.

The internal plastic disc anchors the device to the inside of the stomach wall, while the tube itself is brought out through the incision. The triangular plastic anchor rests on the skin of the abdomen to hold the device firmly in place. The free end of the tube is cut to a manageable length, clamped and attached to a feeding connector.

Radiologically

This method uses x-rays and other imaging techniques to insert the gastrostomy device. It is carried out by an interventional radiologist (doctor specialising in scans and imaging to perform procedures), usually in the radiology (x-ray) department.

The evening before the procedure, your child will need to swallow some barium, usually in the form of a milkshake. Alternatively, it can be given through a naso-gastric tube. Barium is a chalky liquid that shows up well on x-rays. By the next day, the barium will have travelled through the digestive system to

the large intestine, so that this is very clear on the x-rays used during gastrostomy insertion. This helps the radiologist to insert the gastrostomy tube safely.

Once your child is asleep, their abdomen will be cleaned with antiseptic solution. An ultrasound scan will be used to locate your child's liver and its position marked with a pen on their skin. The team will then set up x-ray machines around your child so that images of their abdomen can be seen clearly on a screen near the operating table.

A naso-gastric tube will be passed into the stomach, if your child does not already have one. This is used to fill the stomach with air so that it is easier to reach from the skin. Using a series of catheters and guide wires, the interventional radiologist will place the gastrostomy device through the stomach wall, having pulled it down through the mouth and into the stomach.

The internal plastic disc anchors the device to the inside of the stomach wall, while the tube itself

is brought out through a small incision. The triangular plastic anchor rests on the skin of the abdomen to hold the device firmly in place. The free end of the tube is cut to a manageable length, clamped and attached to a feeding connector. The naso-gastric tube is usually removed at this stage.

If it not possible to place the device radiologically, your child will be transferred to another team at GOSH for insertion using another method.

Surgically

An open gastrostomy insertion is the placement of a gastrostomy tube directly into the stomach using an open incision through the abdominal wall under general anaesthesia. It is carried out by a surgeon in the operating theatre.

Once your child is asleep, their abdomen will be cleaned with antiseptic solution. Local anaesthetic is used at the site of the incision so that it is not too uncomfortable when your child wakes from the general anaesthetic. An incision

is made in the upper abdomen near where the gastrostomy is to be placed. The stomach is identified and stitches are put in place to secure the stomach to the abdominal wall. A Malecot® tube is passed through the skin and into an opening made in the stomach. This tube is stitched in place and the incision is closed using dissolvable stitches under the skin.

Are there any risks?

There is a very small possibility that during the procedure, the doctor will not be able to insert the gastrostomy device using the method planned, in which case your child would need to have it inserted another way. This may have to be done on a separate occasion.

All gastrostomy sites may leak onto the skin or become inflamed where the device passes through the skin. These complications can usually be managed on the ward and at outpatient visits.

With endoscopic insertion, there is a risk that the endoscope could damage your child's oesophagus

(food pipe) or stomach during the procedure. This is very rare as the endoscope is very flexible. There is a small risk that the large bowel or other organs may be damaged during this procedure with the passage of the needle.

There is a very small chance that the large intestine could be damaged during radiologic insertion, but using barium beforehand reduces this risk. If your child has not had barium the night before the procedure, the consultant may cancel the operation as the risk of damaging the large intestine may be too great.

With a surgical insertion, the use of a larger incision may increase your child's discomfort after the operation. This is something we can treat with pain relief medication. Your child will also have a small scar at the site of the incision.

What happens after the operation?

Your child will be moved back onto the ward when they have woken up from the anaesthetic. They may feel a bit groggy for a few hours afterwards. The nurses on the ward will keep a close eye on your child's gastrostomy to make sure there are no problems. They will also keep a check on your child to make sure they are recovering well from the anaesthetic.

Your child may have a drip for the first day or so after the operation. Their abdomen may look a little red and ooze a bit, but this will settle down in a few days. It may also feel a bit sore for a few days after the operation, but usually mild pain-relieving medicines are enough to relieve any pain. Once the area has settled down, your child will probably hardly notice the gastrostomy.

The gastrostomy can be used straightaway for medicines. A few hours after the operation, they will be fed for the first time through

the gastrostomy device. The nurses will start with a small amount of water and wait to see how your child is tolerating it. If everything is fine, they will give a small amount of clear feed, again waiting to see how your child tolerates it. If there are no problems, they will give a small amount of your child's usual feed, increasing the amount over the next few hours.

Gastrostomy feeding

A dietitian will have discussed with you the most appropriate method of feeding your child. This depends on your child's medical condition, the particular needs of your child and family and your home circumstances. Some children only use the gastrostomy for medicines or fluids, rather than for feeds.

There are three different methods of feeding your child using the gastrostomy – bolus (intermittent), continuous or a combination of both. For example, bolus feeds during the day and a continuous overnight feed. A bolus is a specific amount of feed which is

given in one go (usually over 20 minutes). If your child is being fed continuously, he or she will receive the feed slowly over a number of hours through an electric pump. If this equipment is required, your dietitian will have contacted your community team or the feed company to arrange for you to be trained to use the pump safely.

Your child will have a special liquid feed, which contains all or most of the nutrients he or she needs. Please talk to your dietitian if you would like to know more about it. There is no need to add flavouring to the feed – your child will not taste it as it goes directly into their stomach. Some children can continue to eat regular food by mouth, using the gastrostomy to ‘top up’ their nutrient levels, but this depends on the reasons why the gastrostomy is required.

You will need to ‘flush’ the device before and after giving feeds or medicines. We will show you how to do this.

Going home

You will be able to go home once your child has recovered from the operation and you are confident about dealing with the gastrostomy. In some cases, you may be able to go home after an overnight stay.

Gastrostomies can sometimes develop problems in the first few days after insertion. If any of the following occur, do not give any feed or medicine and take your child to your local Accident and Emergency Department.

- Your child is in severe pain immediately if a feed or medicine is given through the gastrostomy
- There is any bleeding from the gastrostomy
- The feed or stomach contents are leaking from the gastrostomy

Follow up appointments

As children having a gastrostomy device inserted can be under the care of a number of different teams at GOSH, they may not need a follow up appointment with the team that inserted the device. Follow up appointments and care will usually be with your child's original team.

On-going care of the gastrostomy

Once the stoma has healed, it can be washed and dried. You should keep your child's gastrostomy clean by washing it once a day and then patting it dry with a towel. Do not rub the stoma site as this will make it sore. This is a good opportunity to check that the skin around the stoma is not sore or infected. If you see any changes and are worried, please call your community paediatrician or GP for advice.

The triangle holding the PEG in place should not dig into your child's abdomen although it must fit snugly against the skin. You may need to

adjust it if they become bloated or gain weight. The triangle should not be adjusted until 10 days after the operation. The nurses will show you how to do this before you go home. Wearing a close fitting vest can stop it getting tangled up, trodden on or accidentally pulled.

Sometimes the gastrostomy can leak a little, but you just need to clean the area with some damp gauze. If it carries on leaking, the ooze is a yellow/green and has an odour or the skin around the site is irritated, please call your GP or community nurse for advice.

Once the PEG has been in place for 10 days, you should advance and turn the tube once a week. This stops the internal disc from sticking to the stomach wall. If the area looks red or is oozing, or your child finds it painful, do not turn the tube and ask your community team for advice.

It is very unlikely that a PEG device will fall out due to its design, as it has a circular disc inside the stomach holding the device in place. It is possible, however, that

the end of the tube inside the stomach could move. Some tubes have measurements marked on them, so you can easily see if it has moved. Your child may also show the following signs if the tube has moved:

- Sudden diarrhoea (runny poo) following a feed
- Pain or discomfort
- General signs of being unwell, such as a high temperature, vomiting or a bloated stomach.

It is also unlikely that a Malecot® tube will fall out as it has been secured with stitches. It should also be secured to the skin using tape or a dressing. If it becomes loose or falls out within four weeks of insertion, please contact the team at GOSH to arrange for it to be re-inserted.

If you are concerned, please contact your community team. Out of hours, you should take your child to your local Accident and Emergency (A+E) department.

Support at home

Your local community health care team will be able to help you. This may be your local paediatric community nurse, if your area has one or your local GP surgery or the local feed company nurse. All children should be under the care of a dietitian, either in their local area or at GOSH. If you have any worries you can always ring your community team for advice and support.

Medicines

When medical staff are prescribing medication, remind them your child has a gastrostomy. Tablets may block the tube, so liquid medicine would be better. If you need to give medicines in tablet form, make sure they are finely ground and mixed with cooled boiled water. You can buy a tablet crusher from your local community pharmacy to make this easier. Always check with the pharmacist that the tablet can be crushed as some have a special coating to allow them to be slowly released in the stomach.

Always flush the gastrostomy well after giving the medicine (you will have been shown how to do this by the nurses on the ward). Medicines should never be mixed together in case they interact. Give each medicine separately and flush the device with a small amount of water in between each one. This will stop the tube becoming blocked.

Equipment and supplies

We will give you a spare nasogastric tube or gastrostomy device to take home with you. If the device falls out, you will need to insert the spare tube or device into the stoma straight away, otherwise the stoma will close. The nurse will advise you about when it is safe to do this.

You will receive further supplies from your community health care team, your local paediatric community nurse (if your area has one), your dietitian or your GP. If you have any problems getting hold of further supplies once you are at home, please ring the hospital.

You should remember to order new supplies in good time before you run out and only use equipment for the length of time specified by the manufacturer. Using or re-using equipment against the advice of the manufacturer could lead to infections, causing a nasty bout of diarrhoea and vomiting which could harm your child.

Your child's gastrostomy supplies do not have any special requirements for waste disposal. They can be put in your usual household rubbish, although we advise that giving sets and syringes are put in a plastic bag before putting in the bin.

Getting back to normal

Mouth care

Your child should still continue to clean their teeth twice a day and visit the dentist regularly. If your child's mouth feels dry and they cannot safely have a drink, a fine water spray bought from the chemist can make your child's mouth more comfortable. Lip balm can help dry cracked lips.

Showers and baths

Until the gastrostomy site has healed, you should clean it as shown by the nurse. After the site has healed, your child can shower and bath as normal. Always make sure that you dry around the stoma, as any dampness can breed bacteria and develop into an infection.

Nursery and school

Your child should be able to go to school as normal. Your community team, social worker or the special needs co-ordinator (SENCo) at the school will be able to advise you further about this. If necessary, staff at the school can be taught what to do if the device falls out.

Swimming and PE

Your child will be able to go swimming once the gastrostomy site has healed, as long as he or she does not have any other problems which prevent this. Your nurse will advise you when it is safe to start swimming. Children with a Malecot® tube should not go swimming until it has been changed to another device. If your child particularly enjoys contact sports, ask the medical team for advice.

Holidays

It is fine to travel with your child. However, if your child has complex needs you should discuss your travel plans with the doctor. Remember to take extra supplies with you, in case you end up staying longer than you planned. If you are planning a beach holiday, cover the gastrostomy with a large dressing to stop sand getting into it. Sand can irritate your child's skin near the stoma site, cause an infection or damage the device itself.

If you want to travel abroad with your child, please contact PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) – see *Useful numbers* for details. They can provide you with information on how to arrange insurance, get supplies abroad if necessary and other useful information.

It may be helpful, particularly if your child has other complex needs, to take a letter from the relevant consultant at GOSH explaining your child's medical history. This will help if you need to seek medical advice locally.

If you are planning to fly to your holiday destination, remember to carry some equipment in your hand luggage, in case your suitcases go missing. You should also carry a letter from your consultant explaining that you are carrying medical equipment because of your child's feeding needs. This should prevent any problems with airport security.

Trouble shooting

What if	Action
My child feels sick and has stomach cramps	<ul style="list-style-type: none"> ■ Check the rate of feeding. You may need to slow down the feeding rate. ■ The feed may be too cold. Let the feed reach room temperature before giving it to your child.
My child has diarrhoea	<ul style="list-style-type: none"> ■ Check the rate of feeding. You may need to slow down the feeding rate. ■ If diarrhoea continues, contact your family doctor (GP).
My child is vomiting	<ul style="list-style-type: none"> ■ Check the rate of feeding. You may need to slow down the feeding rate. ■ If you are using commercially-prepared feeds, always check the expiry date. ■ The feed may be too cold. Let the feed reach room temperature before giving it to your child. ■ 'Vent' (or remove wind) in the way you have been shown. Attach an empty syringe to the tube to allow air to escape.
My child's stomach is swollen and hard after feeding	<ul style="list-style-type: none"> ■ 'Vent' (or remove wind) in the way you have been shown. Attach an empty syringe to the tube to allow air to escape.
The gastrostomy device seems to be blocked	<ul style="list-style-type: none"> ■ This may be due to inadequate flushing or a very thick feed or medication. Try flushing the tube with warm water or fizzy soda water and hold the syringe high so the water moves more easily. ■ Move the plunger of the syringe in a push/pull motion and wrap a warm flannel around the length of the tube, massaging it gently with your thumb and fingers. If the device continues to be blocked, call your community team for advice.

What if	Action
<p>The gastrostomy site seems red or is bleeding, oozing, irritated or swollen and my child has a temperature</p>	<ul style="list-style-type: none"> ■ If this occurs within 72 hours of insertion, do not give any feed or medicine and take your child to your nearest Accident and Emergency department. ■ Check the site around the gastrostomy button daily. ■ Clean if the feed or medication comes into contact with your child's skin. ■ If the site remains irritated, you may need to use a soft dressing to absorb ooze and act as a barrier. ■ If your child has a temperature, contact your community team to arrange for a swab and a prescription for antibiotics or antifungal treatment.
<p>The tube falls out</p>	<ul style="list-style-type: none"> ■ Insert a spare naso-gastric tube or gastrostomy device into the stoma to stop it closing up. ■ Take your child to your local hospital so that a new device can be inserted. ■ You should have a spare device to take with you.

Useful telephone numbers

Gastrostomy Service

– 020 7405 9200 ext 5695 or bleep 0321

PINNT (Patients on Intravenous and Nasogastric Nutrition

Therapy) is an organisation for anyone receiving tube or intravenous feeds. They have a special section for children and young people called Half PINNT. Visit their website at www.pinnt.com.

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Great Ormond Street Hospital for Children NHS Foundation Trust
Great Ormond Street
London WC1N 3JH

www.gosh.nhs.uk