

Gastrostomy care



Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

A gastrostomy is a surgical opening through the skin of the abdomen to the stomach. A feeding device is put into this opening so that feed can be delivered directly into the stomach bypassing the mouth and throat. This information sheet from Great Ormond Street Hospital (GOSH) describes the operation to create a gastrostomy and explains the care it will need afterwards.

Key points

- A gastrostomy is an opening through the skin into the stomach – this is created in an operation under general anaesthetic.
- A feeding device is put into this opening to deliver feed directly into your child's stomach, bypassing their mouth and throat.
- The feed solution contains all the nutrients your child needs to grow and develop. Medicines can also be given using the feeding device.
- The initial feeding device stays in place from six weeks to two years – how long depends on the device used – and is then changed either for the same type again or a different one.
- We will show you how to take care of the gastrostomy site – following instructions will reduce the risk of complications.
- If your child experiences severe pain, bleeding, or leaking from the gastrostomy within the first few days of insertion, do not use it to give any feed or medicine. Call the team at GOSH (or the On Call Surgical Registrar out of hours) for urgent advice.

Why might a gastrostomy be suggested?

A gastrostomy can be helpful for anyone who needs long term support with feeding or to receive extra nutrients to grow and develop.

Some children and young people have a neurological (nervous system) disorder that affects their swallowing which increases the chance of breathing in food (aspiration).

Others may have a gastrointestinal (digestive system) disorder that affects how food travels down the oesophagus (food pipe) into the stomach. Delivering feed directly into the stomach can be helpful in dealing with these problems.

As well as using it for feeding and medicines, a gastrostomy can also allow gas to be 'vented' from the stomach to reduce bloating or to drain stomach contents.

Some children and young people have a gastrostomy as part of a particular treatment protocol, often for blood and cancer disorders. In these cases, the gastrostomy device may be used mainly for giving medicines but can also 'top up' nutrition if they do not feel like eating and drinking much.

Many children and young people who have a new gastrostomy will already have been feeding using a naso-gastric tube, which is a thin plastic tube inserted into the nostril and passed down the food pipe into the stomach. While this is an effective way of feeding directly into the stomach, a gastrostomy offers a more suitable long term solution that is also less visible.

The clinical team will explain why a gastrostomy might be the most suitable option for feeding and you will be able to discuss what the best feeding device is for your child.

Different types of feeding device

There are three main types of feeding device that are inserted into the gastrostomy opening at GOSH. Different types or brands may be used elsewhere, and though principles in caring for them are broadly similar, you should receive specific advice for the type and brand from the manufacturer or specialist.

The device that is initially inserted into the new gastrostomy site is often called a primary device, this is to indicate the importance in careful management until the stoma is healed and established, and the first device change has taken place.

Primary devices



The initial device most commonly used at GOSH is called a Freka® PEG. This consists of a flexible polyurethane tube which is held in place in the stomach with a silicone disc. A triangular silicone fixator holds it in place on the skin of the abdomen. The free end consists of a port with a closure cap, to which a 'giving set' is connected when feeding.



A Malecot® catheter may also be used as a primary gastrostomy device. This is a multifunction tube that is used in various locations in the body. When used as a gastrostomy feeding device, it is held in place in the stomach with wide, flat wings and a stitch, and then the outside portion is secured to the abdomen with a dressing. This is usually a short term device that will be changed after around six weeks, usually to a Mic-key™ button.

A Mic-Key™ button is a low profile balloon device and is also sometimes used as an initial or primary device. A primary Mic-key™ button will need special care until the gastrostomy is healed to make sure that it stays in place with the balloon and stitches.

Secondary devices



Primary devices usually remain in place for six weeks (Malecot®), six months (Mic-Key™ button) or between six months and two years (Freka™ PEG).

If a Mic-Key™ Button was not the primary device, it is usually the preferred secondary device as it is held in place in the stomach with a balloon – there is a port outside the button to insert water into the balloon to inflate it. The external part of the device is described as ‘low profile’, that is, it lies flush to the abdomen. A connector set is attached to the port to give feeds. Unlike Freka™ PEG, a Mic-Key™ button can be replaced without a general anaesthetic often by community teams and families. If a Freka™ PEG is the most suitable device for your child, this can also be used as a secondary device.

Are there any alternatives to having a gastrostomy?

The main alternative is to carry on using a naso-gastric tube for feeding. Some children and young people struggle with the appearance of the tube as well as disliking the procedure to insert a new NG tube, which can be quite painful or traumatic. There is also a risk of the NG tube being displaced into the lungs, and some areas will not allow overnight feeding via this route for this reason.

Another alternative is having total parenteral nutrition (TPN) where nutrition is delivered into the blood stream using a central venous access device inserted in an operation under general anaesthetic. As the device is connected to the blood stream, there is a risk of serious infection, and this is usually considered as a last resort when people have no other way to gain nutrients.

Creating the gastrostomy and inserting the first device

The gastrostomy opening is always created while a child is under general anaesthetic. Several methods are used at GOSH – we will explain which is most suitable as it depends on a child's weight, size, underlying condition and whether they have had any abdominal surgery before.

Sometimes a gastrostomy is created during another procedure – most commonly an operation called a fundoplication which aims to reduce gastro-oesophageal reflux.

Pre-admission assessment

Your child will need a pre-operative assessment before the operation either immediately after an outpatient appointment or on another day. The aim of this appointment is to check that your child is well enough for the procedure, meet the team and give you an opportunity to ask questions. This visit may include taking blood samples, photographs and swabs. Your child may need to visit the Anaesthetic Pre-assessment Clinic as well for a check-up for the anaesthetic.

The day before the operation

Your child should have a bath or shower and hair wash the night before the operation. They should remove any make up or jewellery or nail varnish.

We will contact you to explain fasting times. Your child must not have anything to eat or drink after the time given in the telephone call. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure. It is equally important to keep giving children food and drink until those times to keep them well-hydrated so you may need to wake them during the night. If you do not follow these instructions exactly, your child's operation may be delayed or even cancelled.

If your child is having the gastrostomy formed radiologically, they will need to have a drink of barium beforehand.

We will also tell you what time to arrive on the day of the operation. Please leave plenty of time for travelling and come to the unit promptly as the surgeon and anaesthetist have to visit you before they start the operating list.

On operation day

Before your child goes to the operating theatre, you will meet the doctor who will explain the operation in detail, discuss any worries you may have and ask you and your child to give permission for the operation by signing a consent form. An anaesthetist will also see you to explain your child's anaesthetic in more detail. If your child has any medical problems, like allergies, please tell the doctors.

When the operating theatre is ready, you and your child will be collected and taken there by a member of staff. You will be able to stay with your child until they are under general anaesthetic and then you will be taken to the post-operative ward. You can wait elsewhere in the hospital but please make sure we know how to contact you.

What does the operation involve?

A gastrostomy can be formed endoscopically (using a camera), radiologically (using x-rays) or surgically (laparoscopically or under direct vision). If one particular method is unsuitable, there are other options that can be considered.

Endoscopically

This procedure uses an endoscope (flexible 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. The endoscope is passed into the mouth and down the food pipe to the stomach which is inflated with air to bring it closer to the surface of the abdomen.

The light on the end of the endoscope is bright enough to shine through the skin to show where to make the incision. If a surgeon is completing the procedure, they may use another small incision and telescopic camera to guide the insertion of the device. The gastrostomy device is fed down through the food pipe to the stomach using a guide string and brought out through the skin incision. The internal disc holds the device in place in the stomach and the triangular fixator holds it securely on the abdominal skin. The free end of the tube is cut to a more manageable length, clamped and attached to a feeding set.

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) in the Interventional Radiology department.

As x-rays are used, children will need to have some barium the evening before the procedure. This usually comes as a milkshake or can be given down an NG tube – it travels through the digestive system to the large intestine so it can be seen clearly during the insertion procedure.

The insertion procedure starts with an ultrasound scan to identify the location of the liver which is marked on the abdomen. The stomach is then inflated with air to bring it closer to the surface of the abdomen. 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 disc holds the device in place in the stomach and the triangular fixator holds it securely on the abdominal skin. The free end of the tube is cut to a more manageable length, clamped and attached to a feeding set.

Surgically

This involves inserting 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.

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 or Mic-key® button is passed through the skin and into the opening made in the stomach. The Malecot® tube is stitched in place and the incision is closed using dissolvable stitches under the skin. The Mic-key® button is held in place in the stomach with a balloon filled with water.

Laparoscopically

Gastrostomy devices can also be inserted laparoscopically (keyhole surgery) using a telescopic camera and a thin instrument under general anaesthesia. It is performed by a surgeon in the operating theatre. A small incision (approximately 15mm) will be made near your child's tummy button so that a telescopic camera can be passed inside to see the stomach and inside of the abdomen. Another incision is made (approximately 15mm) at the point where the gastrostomy is to be placed and a thin instrument is inserted to pick up the stomach wall. The stomach is then stitched to the gastrostomy site and an opening made, into which the tube is placed and secured with another stitch. The incision at the tummy button is then closed using dissolvable stitches beneath the skin.

Are there any risks?

As with all procedures, there is a very small chance that the planned method of insertion turns out to be unsuitable so an alternative approach will need to be considered. This may need to be done on a separate occasion.

As well as the risks of the general anaesthetic, formation of a gastrostomy can cause damage to the foodpipe, stomach or nearby structures. Careful measures are taken to manage these risks. If you are concerned about the risks to your child please discuss with the team performing the procedure.

The new gastrostomy site may be sore following the procedure, and this is usually managed with regular pain relief. The procedure to create the gastrostomy may leave marks or scars.

All gastrostomy devices can irritate the skin around the device but this can usually be managed on the ward and at outpatient visits. For the first few days after insertion, there is a risk of problems developing – we will explain what to look out for and what to do if they happen later in this booklet.

What happens afterwards?

Your child will return to the ward after the procedure to allow them to recover from the anaesthetic. They may have a fluid drip for the first day or so after the procedure. The abdomen may look red and ooze a bit but this will settle down in a few days. The nurses will check your child's pain regularly and give them pain relief to keep them comfortable.

Starting to use the feeding device

Unless the doctor gives special instructions, the gastrostomy device can usually be used straightaway to give your child medicines – if your child took regular medicines by mouth or through the NG tube, a different format may be prescribed to be given through the gastrostomy. The nurses will test the gastrostomy a few hours after the procedure, first with a small amount of water and if everything is fine, next with a small amount of feed. If there are no problems, the amount of feed given will gradually be increased.

A special liquid feed containing all or most of the nutrients needed is used with the gastrostomy. There is no need to add flavouring to the feed as it is delivered directly into the stomach. Liquidised or pureed food should not be given through the gastrostomy. 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. Each time the gastrostomy is used, whether for feed or medication, it should be 'flushed' afterwards to prevent blockages – we will show you this before you go home.

There are three 'regimes' for gastrostomy feeding:

- **Bolus (intermittent)** – a specific amount of feed given in one go, usually over 20 minutes or so, using gravity
- **Continuous** – where the feed is pumped slowly into the stomach over a number of hours
- **A combination of the two** – for instance, bolus feeds during the day and a continuous overnight feed

The dietitian should have discussed the most appropriate feeding method for your child, depending on their underlying condition, any additional needs they have and your home circumstances. If any equipment is needed, this will be arranged locally through community teams or a feed company.

At GOSH, commercial feeds are used over liquidised food for tube feeding ('blended diet'). This is to avoid increased risk of tube blockage (in line with manufacturer guidance) and food contamination, to ensure patient safety.

If children are using the gastrostomy just for medication rather than feeds, the ward team will show you how to use the device before going home.

If the gastrostomy is not being used for medicines or feeds, it still needs to be flushed every day to prevent the tube from becoming blocked, and the ward team will practice this with you before you go home.

Going home

You will be able to go home once your child has fully recovered from the operation and the gastrostomy is working well. 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, such as:

- Severe pain as a feed or medicine is given through the gastrostomy
- Any bleeding from the gastrostomy opening
- Feed or stomach contents are leaking from the gastrostomy opening

Call the team at GOSH (or the On Call Surgical Registrar out of hours) for urgent advice. Do not give any feed or medicine until you have spoken to the team. You may need to go come back to GOSH as for the device to be moved in another operation under general anaesthetic. The team at GOSH will advise you whether to go to your nearest Accident and Emergency (A&E) department.

Ongoing care of the gastrostomy

Once you have returned home, your local community 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.

Skin care

The skin around the gastrostomy opening should be cleaned every day. For the first few days, this should be done very gently to avoid disturbing any stitches or making the area uncomfortable. Once it has healed, it can be washed in the shower or bath as usual and gently patted dry with a towel. Do not rub at the gastrostomy, or use special cleaning solutions or 'wipes' as this may irritate the gastrostomy. You should also check the skin around the opening while washing to make sure it is not infected or sore.

Sometimes a gastrostomy can leak a little but you just need to clean the area with some damp gauze. A small amount of mucus is normal – this may look like the 'sleep' crusts around the eye on waking – but if it carries on leaking and the ooze smells, or the surrounding area looks inflamed or feels hot to touch, call your community team or family doctor (GP) for advice.

Care of a Freka® PEG

The triangle holding it in place should not dig in but must fit snugly against the skin. Do not adjust the triangle for the first 10 days of the operation, while the opening is establishing. After this, you can adjust the triangle if there is any bloating or weight gain. At this point you should also advance and turn the device once a week. Some tubes have measurements marked on them, so you can easily see how much to advance and turn it. Wearing a close fitting vest can stop the tubing getting tangled up, trodden on or accidentally pulled. This device is usually left in for up to two years. When the date for change is approaching, please contact the hospital to organise a suitable date. It is very unlikely that the device will fall out due to its design, as it has a circular disc inside the stomach holding the device in place. If it does fall out or feels loose, go to your local hospital urgently and contact the Gastrostomy and Stoma team at GOSH.

Care of a Malecot® tube

This is unlikely to need much attention other than gentle cleaning around the opening, as it is a temporary device. The site often has more mucus or might appear a little red, as the tube contains latex to irritate the new stoma and help it heal. This device is usually left in for six weeks before being changed to a Mic-key™ button at the hospital. When the date for change is approaching, please contact the

Gastrostomy and Stoma team at GOSH to organise a suitable date and time for you to attend. It is unlikely to fall out as it is stitched in place. If it does fall out or feels loose, go to your local hospital urgently and contact the team at GOSH.

Care of a primary Mic-key™ button device

This is also unlikely to need much attention in the first few weeks other than gentle cleaning around the opening. The device is unlikely to fall out as it is held in place by the balloon. The water in the balloon should not be removed or changed for the first six weeks after the procedure. It is often preferred to leave the feeding extension on for the first 48 hours to avoid disturbing the site by attaching/re-attaching it. The primary button is usually left in for six months. When the date for change is approaching, please contact the Gastrostomy and Stoma team at GOSH to organise a suitable date and time for you to attend. If it does fall out or feels loose, go to your local hospital urgently and contact the team at GOSH.

Equipment and supplies

We may 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 opening straight away, otherwise it will close. The nurse will advise you about when it is safe to do this. Otherwise, you must take your child to your nearest Accident and Emergency (A&E) department for them to maintain the opening.

You will receive further supplies from your community or feed care team. If you have any problems getting hold of further supplies once you are at home, please ring the Gastrostomy and Stoma team at GOSH. 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 infection, causing a nasty bout of diarrhoea and vomiting which could be harmful.

There are no special requirements for disposing of gastrostomy supplies – they can be put in your usual household rubbish, although we suggest you put giving sets and syringes in a separate plastic bag before putting in the bin.

Giving medicines

When medical staff are prescribing medication, remind them about the 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. Medicines should never be mixed together in case they interact – give each one separately and flush the device with a small amount of water in between each one. This will help prevent it getting blocked.

Mouth care

Even if your child is no longer eating and drinking by mouth, they should still be brushing their teeth twice a day and visiting the dentist regularly. If their mouth feels dry and they cannot safely swallow liquid, a fine water spray can make things more comfortable. Lip balm can also help any soreness or cracking.

Nursery and school

Your child should be able to go to school or nursery as usual. Talk to your community team or school staff for further advice – they may be able to teach what to do if the device falls out.

Sport and swimming

For most children, swimming is fine once the gastrostomy opening has established, so long as they have no other problems for instance with their immune system. Children with a Malecot® tube should not go swimming until it has been changed for a secondary device.

Sport should not be a problem but we tend to advise against contact sports, due to the risk of the device being dislodged or damaged. Talk to the team about particular sports your child enjoys.

Holidays

Most children and young people can travel within the UK and abroad when they have a gastrostomy. If your child has additional needs, it may be wise to discuss your travel plans with your doctor before making any bookings. Carrying a letter from them will be helpful for getting through security and if you need to seek advice when you are away. If you are flying, always carry some of your child's equipment in your hand luggage, in case the hold luggage goes astray. The support organisation PINNT – see details later – can advise about holiday insurance and foreign travel.

Device changes

The initial gastrostomy device – except for the temporary Malecot® tube – usually needs to remain in place for at least six months for the opening to establish and can then stay in place for up to two years. After this, it will need replacing as the plastic will be starting to wear out and weaken. When a primary Mic-Key™ button has been in place for five months, or a PEG has been in place for around 18 months, call the team at GOSH to arrange an appointment to discuss the device change. After the initial device, you and your child will be able to choose whether to have the same device again or change it to a balloon device – either a low-profile button or a tube held in place with a water-filled balloon. If your child is continuing with a Freka® PEG, they will need to have this replaced under general anaesthetic, but balloon devices can often be inserted while your child is awake.

Following the first change, Mic-key™ buttons are usually changed at home by parents or the community nursing team. While your child is still receiving care and treatment at GOSH, you will need to contact the team every 18 months or so to arrange change of a Freka™ PEG. If your child is discharged from GOSH, they may need to be referred back for a change of the device by your local hospital or GP. As they grow older, we will get them ready to move onto an adult hospital where their care (including gastrostomy care) will continue.

Trouble shooting

The gastrostomy opening is red, bleeding, oozing, irritated or swollen

- If within three days of insertion
 - Do not give any feed or medicine
 - Call the team at GOSH (or the On Call Surgical Registrar out of hours) for urgent advice.
 - You may need to go come back to GOSH for the device to be moved in another operation under general anaesthetic. The team at GOSH will advise you whether to go to your nearest Accident and Emergency (A&E) department.
 - After this
 - See advice from your community nursing team or GP. You can also call the GOSH Gastrostomy and Stoma nursing team.
 - Use a soft antimicrobial dressing to absorb ooze and stop the device rubbing.

Feeling sick with a crampy stomach after a feed

- Check the rate of feeding – you may need to slow down
- Check if the feed is too cold – let it reach room temperature

Swollen or hard stomach after a feed

- 'Vent' (or remove wind) in the way you have been shown. Attach an empty syringe to the tube to allow air to escape.

Device blockage

- 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 or feed company team for advice

New or increased diarrhoea (runny poo)

- Check the rate of feeding – you may need to slow down
- Check whether the device has moved
- Contact your family doctor (GP), or community nurse for advice

New or increased vomiting

- Check the rate of feeding – you may need to slow down
- Check the expiry date on the feed package – if it has passed this date, tell your community or feed company team
- Check if the feed is too cold – let it reach room temperature
- 'Vent' (or release wind) in the way you have been shown – attach an empty syringe to the device to allow air to escape
- Contact your family doctor (GP), or community nurse for advice

The device falls out

- Insert the spare naso-gastric tube or new device into the opening to stop it closing
- Take your child to your nearest Accident and Emergency (A&E) department.
- Remember to take the spare device with you

Further information and support

Call the Gastrostomy and Stoma nursing team on 020 7405 9200 extension 5695 or email gos-tr.stoma.nurses@nhs.net

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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