

The Children's Hospital

Gastrostomy

Information for parents and carers



What is a gastrostomy?

A gastrostomy is a tube which is inserted through the abdominal wall (tummy) into the stomach.

There are two common types of gastrostomy, Percutaneous Endoscopic Gastrostomy devices (PEGs) and low-profile 'Buttons'.

Why does my child need a gastrostomy?

A gastrostomy is usually needed if your child has feeding difficulties, for example, if they are unable to get the calories they require from feeding by mouth; if they have an 'unsafe swallow'; or if they have certain other medical conditions.

Percutaneous Endoscopic Gastrostomy device (PEG) (e.g. Corflo PEG, Freka PEG)

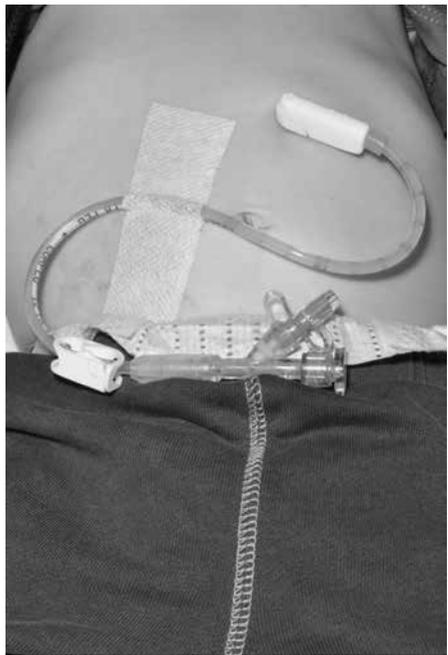
If your child is to have this type of gastrostomy they will need to have an operation under general anaesthetic. This means your child will be asleep throughout the operation.

The PEG is placed into their stomach using an endoscope (narrow tube and camera), which is put in through your child's mouth.

The PEG tube has a soft flange (piece of foam) on the inside of the stomach, to hold the PEG in place. It also has an external plastic 'bolster' on the outside of your child's tummy, which holds the PEG in place and prevents it from travelling back into the stomach.

This type of gastrostomy is usually the first choice of device, as it allows the stomach wall and abdominal wall to join together, while forming a channel (tract) for the gastrostomy.

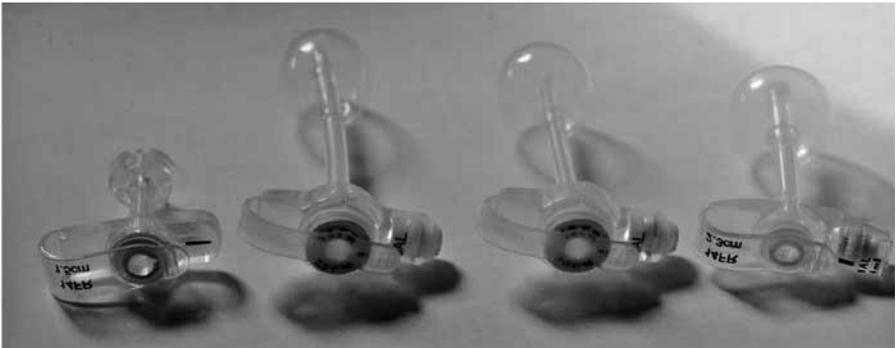
Your child will need to come back into hospital for another operation to change the PEG tube or fit a Button device. This will usually be after 6-12 months; to allow the gastrostomy tract to heal. Your surgeon will discuss this with you at your child's post-operative follow-up appointments.



Low-profile Button (e.g. Mini Button, MIC-KEY, Medicina)

The Button is a smaller device, which doesn't stick out as much from your child's tummy. It has a detachable extension set, which is used to give feed or medications.

The Button is held in place by a small balloon filled with water which, when inflated, sits inside against the stomach wall. The outer part of the Button keeps the device secure on the outside of their tummy.



The water must be checked **weekly** to make sure the balloon is still inflated and not leaking. Your nurse will show you how this is done before your child is discharged home from hospital. However, it will be checked the first few times by the Community Nurse or Complex Needs Team.

Occasionally, a low-profile button without a balloon is used. We will tell you if your child has one of these.

What are the risks?

All operations carry some risks. There is a small risk of bleeding, infection and damage to nearby organs, such as the bowel. There is also the risk that the gastrostomy tube might be inserted in an incorrect position, which may not be discovered until later on.

Risks which may develop after the operation include:

- infection where the gastrostomy tube has been put in
- movement of the tube (either out of position or further down into the stomach or bowel)
- blockage of the tube from food/milk or medicine
- leakage of stomach contents/feed around the gastrostomy site, out onto the tummy.

Anaesthetic risks

In modern anaesthesia, serious problems are uncommon. Risk cannot be removed completely, but modern equipment, training and drugs have made general anaesthesia a much safer procedure in recent years.

Most children recover quickly after their operation and anaesthetic. Some children may suffer side effects like sickness or a sore throat. These usually last only a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your child's medical condition and on the nature of the surgery and anaesthesia your child needs. The anaesthetist can talk to you about this in detail before the operation.

Consent

The doctor will explain the operation in more detail and talk with you about any concerns you may have.

An anaesthetist will also visit you to discuss the anaesthetic your child will have for the operation. They will also talk with you about the pain relief which your child will need after the operation.

We will ask you for your written consent (agreement) for the operation to go ahead. If there is anything you are unsure about, or if you have any questions, you can ask the doctor both before and after signing the consent form.

Pain assessment

Your child's named nurse will use a pain assessment tool to help assess their pain score after their operation. This is a chart which helps us to gauge how much pain your child may be feeling. You and your child will be introduced to this assessment tool either at their pre-assessment visit or on the ward before their operation. You can continue to use this assessment at home to help manage your child's pain if you wish.

Pregnancy statement

All girls aged 12 years and over will need to have a pregnancy test before their operation or procedure. This is in line with our hospital policy.

We need to make sure it is safe to proceed with the operation or procedure, because many treatments including anaesthetic, radiology (X-rays), surgery and some medicines carry a risk to an unborn child. The pregnancy test is a simple urine test and the results are available immediately. If the result is positive we will discuss this and work out a plan to support your child.

Preparing for coming to hospital

You will be given instructions which tell you how to prepare for your child's operation before they come to hospital.

Please make sure that you follow the fasting (starving) instructions which should be included with your child's appointment letter. Fasting is very important before an operation. If your child has anything in their stomach whilst they are under anaesthetic, it might come back up while they are unconscious and get into their lungs, with serious consequences.

You will also be given instructions on what to do about giving any medication that your child usually takes, whilst they are fasting before the operation. Please make sure that you bring any medications that your child usually takes with you when you come into hospital.

What will happen on the day of the operation?

Your child will be seen by an anaesthetic doctor, surgical doctor and a nurse, in preparation for the operation.

Your child is likely to be given medication (a phosphate enema) to clear their bowel.

A nurse and one parent/carer can go with your child to the anaesthetic room. Your child can also take a toy or comforter.

It may be possible to give the anaesthetic with your child sitting on your lap. Your child may either have anaesthetic gas to breathe or an injection through a cannula (a thin plastic tube that is placed under the skin, usually on the back of the hand). Local anaesthetic cream (EMLA or Ametop, sometimes known as 'magic cream') can be placed on their hand or arm before injections so they do not hurt as much. It works well for 9 out of 10 children.

If the anaesthetic is given by gas it will take a little while for your child to be anaesthetised. They may become restless as the gases take effect. If an injection is used, your child will normally become unconscious very quickly. Some parents may find this frightening.

Once your child is asleep you will be asked to leave quickly so that the medical staff can concentrate on looking after them. The nurse will take you back to the ward to wait for your child.

Your child will then be taken into the operating theatre to have the operation. The anaesthetist will be with them at all times.

How is the operation carried out?

A narrow flexible tube called an 'endoscope', fitted with a tiny camera, will be gently passed through your child's mouth and into their stomach. The surgeon will make a small incision (cut) on the outside of your child's tummy, through which they will fit the gastrostomy. They will be able to see that the gastrostomy is placed properly on the inside of the stomach, using the endoscopic camera.

The incision on the outside of your child's tummy will heal around the gastrostomy device.

Occasionally the gastrostomy tube cannot be safely inserted using the endoscope. In this situation your child's surgeon may need to use a laparoscope for a clearer view. This will be inserted through another small cut on your child's tummy.

Sometimes, a larger cut will need to be made on the tummy (an open procedure). We will usually discuss this with you before the operation, if it is likely to need to be done.

After the operation

You will be able to go and see your child in the recovery room as soon as they are awake.

Their nurse will make regular checks of your child's pulse, temperature and wound. They will also make sure your child has adequate pain relief during their stay and when they go home.

Care and use of a gastrostomy

The first 48 hours

If this is the first time your child has a gastrostomy, their surgeon will decide when it can start to be used. The dietitian will give you a written feeding plan to follow, which meets your child's specific nutritional needs. The dietitian will also arrange for you to have pump training and for the equipment to be delivered to your home.

The gastrostomy can usually be used immediately for giving medication and feeding can normally start after 24 hours.

Going home

Your nurse will explain and teach you how to use and care for the gastrostomy before your child leaves hospital.

Your child will be discharged from hospital with a two week supply of feeds, equipment, syringes, feeding sets and a feeding pump (if required).

Your child's Community/Complex Needs Nurse will be given a copy of the feeding plan from their dietitian and also the discharge document from their surgeon. This is to make sure that they know which type and size of gastrostomy device has been used.

If your child does not have a Community/Complex Needs Nurse, their hospital nurse will make a referral to your local community children's nursing team. They will be able to give you extra support and advice once your child is discharged home.

Some children may need their gastrostomy venting to help release trapped wind; your nurse will teach you how to do this.

If your child has been fitted with a low-profile Button gastrostomy device, you will also be given a spare extension set and emergency set should the Button fall out.

Daily care

Cleaning

It is important to clean around the gastrostomy site every day. You can do this either with gauze squares, cotton buds or a clean face cloth (only to be used for the gastrostomy).

Wash your hands thoroughly before you clean or touch the area near the gastrostomy. To start with, only use clean, warm water. You can start to use a mild soap when the site is healed. Clean underneath the external bolster and dry thoroughly with gauze or cotton buds. Once the site is completely healed, you will be able to gently dry it with a clean towel.

Two weeks after the operation, the external bolster on the Corflo (or the clamp on the Freka (yellow 9Fr, blue 15Fr)) should be released and cleaned. Your Community/Complex Needs Nurse will show you how to do this the first time and will support you when doing this in the future.

Your child will be able to have a bath after seven days and can go swimming after four weeks.

Turning

If your child has a Corflo PEG or a Freka PEG, it is very important that it is turned 360 degrees once **every day**, after 48 hours.

One month after insertion, the external bolster of the PEG tube should be released and the tube **pushed in** for 3-4cm. It should then be pulled back to the original position and re-secured. This should be done every week, to prevent 'buried bumper syndrome' (where the flange becomes buried in the stomach wall).

Low profile Mini or MIC-KEY Buttons and Medicina devices should also be turned **once a day**. Your Community Nurse will show you how to do this and will give you support.

Turning the gastrostomy prevents it from sticking to the stomach

wall and helps to prevent over granulation tissue developing (a red raised area of tissue around the gastrostomy).

To start with, your child may find that this feels a little sore, so it is a good idea to give them a dose of paracetamol thirty minutes before turning. It is also a good idea to clean the gastrostomy at the same time as turning it.

Your nurse will show you how best to secure the gastrostomy to your child's skin, to prevent it being pulled or caught during the day.

Note: If your child has a gastro-jejunal device it should not be turned 360 degrees. However, you should still clean it in the same way. Please discuss this further with the surgeon or nurses.

Low-profile Mini Button – Balloon device

The water in the balloon that is holding the device in place will need to be checked weekly. Your Community/Complex Needs Nurse will be able to show you how to do this and will offer you support.

Checking the site

Check the site regularly, looking for any changes in appearance. If the site looks red and sore, if there is any discharge from the site, or it smells offensive, inform your Community/Complex Needs Nurse. They will take a swab from the site and advise you on the best course of treatment.

Also, sometimes granulation tissue (a red raised area of tissue) appears around the site. This can be treated, so do let your Community/Complex Needs Nurse know if you are concerned.

Blockages

If your child has a Corflo or Freka PEG tube and it becomes blocked, firstly try and flush it with warm water. If that does not work and you are still unable to unblock it you will need to seek advice from your Community/Complex Needs Nurse. If they are

unable to unblock it you will be referred back to the surgeons who will try to unblock it.

Please note: If your child has a Button, never leave any milk or medication in the extension tube. Always flush it well with water before and after use.

What to do if the gastrostomy comes out

It is vital that you immediately place the supplied emergency replacement tube into the gastrostomy hole, as it can close within hours.

- Insert 5cm of the catheter into the gastrostomy hole, to ensure it is in far enough.
- Tape over the catheter, to cover the end and stop it moving around.
- Once in place, contact your Community/Complex Needs Nurse to arrange for a replacement to be fitted or visit your local children's ward or Emergency Department.

If you do not have a tube, go the nearest Emergency Department and ask to have a tube (e.g. Foley catheter) placed in the gastrostomy hole.

Before your child is discharged from hospital you will have been given an emergency kit. This contains:

- a catheter (tube) and/or emergency replacement gastrostomy device
- stopper
- medical tape.

Please keep this with your child at all times, including at school or nursery. We can arrange to show your child's teacher/carer how to use it.

Leaving hospital

Your child will be able to go home once they are feeding well through the gastrostomy and you are able and confident in using and caring for the gastrostomy.

Before your child goes home you should be able to:

- feed them through the gastrostomy
- carry out daily care of the gastrostomy, as explained by your child's nurse
- know how to change the water in the balloon (if required)
- know what to do if the gastrostomy becomes blocked
- know what to do if the gastrostomy falls out.

Before your child leaves hospital their nurse should give you:

- two weeks supply of feeds and syringes
- a catheter and/or emergency replacement gastrostomy device, stopper and medical tape (emergency kit)
- contact details for your Community/Complex Needs Nurse.

How to contact us

If you have any problems after you get home, please contact your Community/Complex Needs Nurse or GP. If you are unable to do this you can telephone the ward for advice:

Tom's Ward

Tel: **01865 234 108** or **01865 234 109**

(24 hours)

Paediatric Surgical Gastrointestinal Nurse

Tel: **01865 231 265**

(Monday to Friday, 9.00am to 5.00pm)

If you have a specific requirement, need an interpreter,
a document in Easy Read, another language, large print,
Braille or audio version, please call **01865 221 473**
or email **PALS@ouh.nhs.uk**

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January 2017
Review: January 2020
Oxford University Hospitals NHS Foundation Trust
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www.ouh.nhs.uk/information

