

Living with a gastrostomy

Information for families

Great Ormond Street Hospital
for Children NHS Trust

Useful numbers

Child's name:

Great Ormond Street
Children's Hospital: **020 7405 9200**

Shared care
hospital:

Community nurse:

Other information:
(Allergies etc.)

Gastrostomy
tube size: make:

Date	<input type="text"/>	Comments	<input type="text"/>
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Inserted by:

This booklet explains gastrostomies and how to care for one at home. It also explains what to expect when your child comes to Great Ormond Street Children's Hospital for treatment.

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

Why does my child need a gastrostomy?

People who have difficulties feeding can benefit from a gastrostomy. There are many reasons why someone might have difficulties feeding, 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). Your doctor will explain to you the specific reasons why your child needs a gastrostomy.

What are the advantages and disadvantages of a gastrostomy?

Gastrostomies are often useful for children who need to be fed gradually, or have had problems with feeding by naso-gastric tube in the past. Some families find a gastrostomy more acceptable than a naso-gastric tube as it can be hidden under clothing. A useful feature of a gastrostomy is that there will be fewer battles over nasty-tasting medicine as some types can be given through the gastrostomy, bypassing the tastebuds altogether. A gastrostomy can be a permanent or temporary measure, as it can be removed when your child no longer needs it.

How is a gastrostomy inserted?

A gastrostomy is inserted in a short operation under a general anaesthetic. For more information, see *What does the operation involve?* on page 5.

Are there any complications with having a gastrostomy?




There are some complications associated with a gastrostomy. These are explained and methods of dealing with them are included in *Your guide to trouble shooting* on page 13.

Are there different types of gastrostomy?

There are several different types of gastrostomy device used at Great Ormond Street Children's Hospital. It is important to discuss the most suitable type for your child at an early stage. The decision depends on his or her medical condition and age, any special needs your child and family have, any other operations your child needs and the surgeon's expertise. You can change your mind at a later date if the device that is chosen no longer suits your child.



These are the main types of devices used at GOSH:

Percutaneous Endoscope Gastrostomy (PEG)	Malecot tube	Balloon device (tube or button)
<ul style="list-style-type: none"> A flexible polyurethane tube which is passed down the throat and into the stomach. The end of the tube is brought out through a small incision in the abdomen to allow access for feeding. 	<ul style="list-style-type: none"> A flexible rubber tube (catheter) which is inserted through an incision in the abdomen. 	<ul style="list-style-type: none"> There are two types available: a gastrostomy tube and a button or low profile device.
<ul style="list-style-type: none"> Can stay in place for about 18 months 	<ul style="list-style-type: none"> Usually a temporary device for the first six to eight weeks, and is then replaced by a balloon device (see right). 	<ul style="list-style-type: none"> The tube can stay in place for about three months, and the button for about six months to one year
<ul style="list-style-type: none"> Held in place using a disk inside the stomach 	<ul style="list-style-type: none"> Held in place using wide, flat wings inside the stomach, but may need to be temporarily stitched to the skin 	<ul style="list-style-type: none"> Both are held in place in the stomach using a small balloon filled with water.
<ul style="list-style-type: none"> A feeding adapter may need to be attached for each feed, depending on the type of equipment used. 	<ul style="list-style-type: none"> It must be secured with tape and the position tested before each feed 	<ul style="list-style-type: none"> A feeding adapter may need to be attached for each feed, depending on the type of equipment used.
<ul style="list-style-type: none"> Removed using an endoscope 	<ul style="list-style-type: none"> Removed by the clinical nurse specialist. No surgery is necessary. 	<ul style="list-style-type: none"> Removed by deflating the balloon. 

The operation

What happens before the operation?

By the time your child has his or her operation, you should already have discussed with the team which device will be most suitable for your child. The doctors will explain the surgery in more detail, discuss any worries you may have and ask formally for your consent for the operation. Another doctor will visit you on the ward to explain about the anaesthetic. The doctors may also ask for some blood samples, to check that your child is well before the operation.

If your child has any medical problems, such as allergies, please tell the doctors about these.

The nurses and play specialists will talk to your child and may give him or her a special colouring book to make sure that he or she understands and is prepared for the operation. The play specialists may show your child a doll with a gastrostomy in place so that he or she is prepared for what his or her tummy will look like after the operation. You will probably have the opportunity to meet other families with children with gastrostomies so you can share their experiences.

What does the operation involve?

There are two main ways a gastrostomy can be inserted.

One method may involve creating a gastrostomy during surgery to the stomach to correct severe reflux. Following this, your child will have a Malecot tube or balloon gastrostomy tube as a temporary device for approximately six weeks. It is difficult to say how long he or she will be away from the ward.

Alternatively, a percutaneous (meaning 'through the skin') gastrostomy is inserted using an endoscope (a tube with a small camera on the end). This is passed down your child's throat and into his or her stomach. The end of the gastrostomy tube is brought out through a small incision in the abdomen to allow access for feeding. If your child is having a percutaneous gastrostomy fitted, you should expect your child to be away from the ward for about an hour and a half.

What are the risks of the operation?

Any surgery carries a small risk of infection or bleeding. Every anaesthetic also carries a risk, but this is very small. Your child's anaesthetist is an experienced doctor who is trained to deal with any complications. The surgeon and anaesthetist will discuss potential risks with you before the procedure. He or she may have a headache, a sore throat or feel dizzy. These side effects are usually short-lived and not severe.

If the doctors are using a percutaneous endoscope gastrostomy or PEG but are unable to put it in the right place, they may have to insert a tube through an incision (cut) into your child's stomach. The doctor will discuss this with you before you sign your consent for the procedure.

What happens after the operation?

Your child will be moved back onto the ward when he or she has woken up from the anaesthetic. It is possible he or she may still feel a bit groggy.

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 he or she is recovering from the anaesthetic.

Your child may have a drip for the first day or so after the operation, his or her 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.

When the doctor is satisfied with your child's progress, he or she will be fed for the first time through the gastrostomy. If your child has a PEG, this can be six hours after the operation, although sometimes it may not be until the next day. Your doctor will give instructions on when the PEG can be used.

Starting gastrostomy feeding

The dietitian will discuss 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. 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.

How will my child feed using the gastrostomy?

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. 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.

When will we be taught how to deal with the gastrostomy?

The nurses on the ward will start to teach you how to look after the gastrostomy soon after the operation. They will teach you how to clean around the gastrostomy and how to feed your child through it. Your community team will help to teach you how to look after the gastrostomy, and if necessary the ward dietitian will explain how to make up the feeds. There will be a lot to learn but we will make sure you are confident before you go home. Although it may feel daunting at first, it will quickly become easier. Remember, there is always someone on the end of the telephone in your local area, to advise and reassure you.

Before you go home, you should feel confident about all of the things on the following checklist - tick them off as you understand them.

- | | |
|---|--------------------------|
| How gastrostomy feeding works | <input type="checkbox"/> |
| Equipment and supplies needed | <input type="checkbox"/> |
| Giving feeds | <input type="checkbox"/> |
| Setting up the feeding pump (if applicable) | <input type="checkbox"/> |
| Looking after the equipment | <input type="checkbox"/> |
| When to change the device | <input type="checkbox"/> |
| What to do and who to contact if the device comes out | <input type="checkbox"/> |
| Skin care | <input type="checkbox"/> |
| Mouth care | <input type="checkbox"/> |
| Giving medications | <input type="checkbox"/> |
| What to look out for | <input type="checkbox"/> |

If your child has a Malecot tube, it will be changed six weeks after insertion. This is usually done at your first out-patient appointment. Your appointment should be arranged before you are discharged home. The nurse specialist will do this and explain how the balloon device works.

When can we go 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. If your child has a PEG you may be able to go home after an overnight stay on the ward, as long as you feel confident about dealing with it.

Frequently-asked questions

What support can I expect when I get 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, the dietitian at the local hospital or your local GP surgery. If you have any worries you can always ring your community team for advice and support.

How do I look after the gastrostomy site?

The stoma site needs to be treated as a wound for the first five days, and the nurse will show you how to care for it. After that 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. It is best to keep a towel specifically for this purpose, as infection may spread between members of your family if you all use the same one. 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.



If your child has a gastrostomy tube, wearing a close fitting vest can stop it getting tangled up, trodden on or accidentally pulled.

If your child has a PEG, the triangle should not dig into his or her stomach although it must fit snugly against the skin. You may need to adjust it if he or she becomes bloated or gains weight. The nurses will show you how to do this before you go home.

Will there be any leakage from the hole around the tube?

Sometimes it 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.

How do I look after my child's mouth?

Your child should still continue to clean his or her teeth twice a day and visit the dentist regularly.

Where do I get the equipment and supplies?

We will give you a spare nasogastric or gastrostomy tube to take home with you. If the device falls out, you will need to insert the spare tube 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.

What should I do about 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 flush the gastrostomy well after giving the medicine (you will have been shown how to do this by the nurses on the ward).

Can my child have a shower or bath?

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.

Will my child be able to go to 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.

What about swimming or PE?

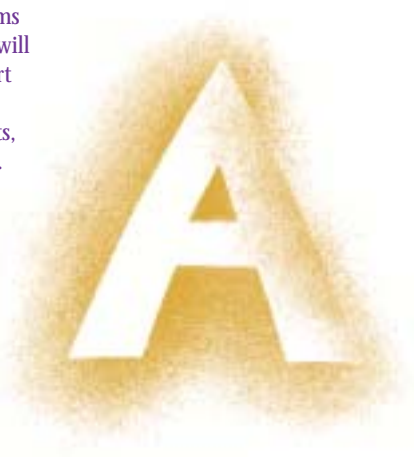
Your child will be able to go swimming once the gastrostomy site has healed, as long as he or she does not have any other problems which prevent this. Your nurse will advise you when it is safe to start swimming. If your child particularly enjoys contact sports, ask the medical team for advice.

What shall we do about mealtimes?

For the sake of the rest of your family, try to keep mealtimes as normal as possible. Encourage your child to join the rest of the family at mealtime, even if he or she is not eating.

Will we be entitled to any extra benefits?

You may be entitled to social security benefits. Please ask to speak to a social worker about this.



Can we go on holiday?

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). The address and telephone number is given under *Support Groups* on the back page. 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.

How will we cope with gastrostomy feeding?

You, your child and the rest of your family may feel from time to time that you are tired of gastrostomy feeding. It affects every family in a different way, but the following are problems that commonly crop up. If you would like to talk through any of the following, please contact your child's community paediatric nurse who will be very happy to help.

• **Keeping things normal**

Try to treat your child as normally as you can. Children who are over-protected or treated differently can become demanding. Your child is only 'different' in the way he or she feeds. Your child will be happier if rules stay the same and life carries on much the same as before.

• **Behaviour problems**

When you leave hospital, you may find your child is more demanding than usual. This is a common reaction to being in hospital, so you should expect it. Your child may become more clingy or revert to earlier behaviour, such as bed wetting, until he or she is used to being at home with you again. If you are worried about your child's behaviour, please talk to your GP or community paediatrician. They may be able to offer you help and advice about settling back into a normal routine once your child returns home.

- **Body image**

Your child may feel self-conscious about his or her tube. Talking to other people can help – you could try contacting the support organisations listed at the end of this leaflet for support and advice.

- **Feeling tied down by gastrostomy feeding**

Your child, you and the rest of your family may feel that everything has to revolve around feeding. Keeping to your normal routine as far as possible – by maintaining the usual mealtimes and bedtimes, for example – may help.

- **Sibling rivalry**

If you have other children, they may feel upset at the attention their brother or sister is receiving. Having ‘special time’ with your other children may help. If relatives and friends seem to focus on the child who has a gastrostomy and pay less attention to your other children, you could ask them to treat all your children equally.

Will my child be able to feed by mouth again?

This depends on the reason why your child needed the gastrostomy. Your team will discuss with you if and when they would like your child to try feeding by mouth again. At first, your child may seem to have ‘forgotten’ how to eat and drink by mouth. If this is the case, a speech and language therapist will offer advice and support. When your child is feeding successfully, the doctors may suggest removing the gastrostomy.

What happens when the gastrostomy device is removed?

The method of removing the gastrostomy device varies according to the type your child has. Your medical team will explain about this nearer the time. Once the device has been removed, the stoma will start to heal. It can take a while to heal completely, so you may need to use a dressing over the site. Once the site is healed, there will be a very small scar.

Unfortunately, your child will not be able to keep the device as a souvenir, as it may carry bacteria and the risk of infection is too great.

Your guide to 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 doctor.
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. • If your child is still vomiting after you have tried the above, draw off a sample of his or her stomach contents (you will have been shown how to do this) and contact your doctor.
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 litmus paper does not turn pink when I test before the feed	<ul style="list-style-type: none"> • Ring your community nurse for advice.
The gastrostomy tube or button 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 tube high so the water moves more easily.
The gastrostomy site seems red or is bleeding, oozing, irritated or swollen and my child has a temperature	<ul style="list-style-type: none"> • 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 anti-fungal treatment.
Stomach contents seem to be leaking through the button	<ul style="list-style-type: none"> • The anti-reflux valve may be stuck or broken. Contact your community nurse.
The button or gastrostomy tube falls out	<ul style="list-style-type: none"> • Insert a spare naso-gastric or gastrostomy tube 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.

Support groups

PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy)

PO Box 3126, Christchurch, Dorset BH23 2XS

Tel: 01202 481 625 (9.30am - 4.30pm, answerphone at other times).

Fax: 01202 481 625 Web: www.pinnt.com

The National Society for Children with Intestinal Disorders

39 The Ridings, Thorley Park, Bishops Cleeve CM23 4EH

Gut Motility Disorders Support Network

Westcott Farm, Oakend, Tiverton EX16 9EZ

Tel 01398 351173

e-mail: help@gmdnet.org.uk

Notes



If you have any questions or concerns, please contact your GP or community paediatric nurse.