



Stoma Care Department

My Child Needs a Gastrostomy (PEG) document

**Information for parents & carers of children
with a Corflo PEG Tube**

What is a PEG?

A PEG (Percutaneous Endoscopic Gastrostomy) is a tube that is inserted into the stomach. It allows a child to be fed directly into their stomach by bypassing the mouth and throat. Most medicines can be given by gastrostomy tube.

Gastrostomies are often used for:-

- children who are unable to take enough food via their mouth to enable them to grow and develop;
- children who need to feed gradually;
- children who have had feeding problems with naso gastric tubes;
- children who are unable to take food or fluid by mouth due to unsafe swallow;



Many families find a gastrostomy tube more acceptable than a naso gastric tube because it can be hidden under clothing.

How is a PEG tube inserted?

The PEG tube is inserted in theatre when your child has had a general anaesthetic. An endoscope, a thin tube with a camera on the end, is used to ensure that the PEG tube is inserted in the correct position. Your child should be in theatre for about 45 minutes.

What happens before the operation?

Before the PEG is inserted you should have already had the opportunity to discuss the operation with the doctors. Once your child is admitted, the doctors will explain the surgery again to you. They will discuss any worries that you may have and ask you to sign a consent form. An anaesthetist will visit your child and discuss the anaesthetic with you.

What are the risks of the operation?

Any operation carries risk a small risk of infection or bleeding and you should have had the opportunity to discuss these before the operation. Your child may wake with a headache, sore throat, feel dizzy or thirsty but these effects usually don't last long and are not severe.

What happens after the operation?

Your child will return to the ward once they are awake from the anaesthetic. They will probably be very sleepy. The nurse on the ward will observe your child to make sure they are recovering from the anaesthetic and have no problems.

Your child's abdomen (tummy) may look a little red and the site of the tube may be moist and ooze a little bit but this will settle down in a few days.

They will also feel a little sore around the gastrostomy site and may complain of general aches and pains. Mild pain relieving medicines are enough to ensure that your child is comfortable and they will require regular analgesia such as Paracetamol for the first few days.

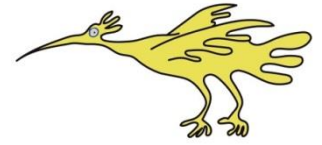
Usually the first feed via the PEG will be when your child wakes up from the anaesthetic

Starting gastrostomy feeds

The dietician will discuss with you the best way of feeding your child. This will depend upon your child's medical condition, the needs of your child and your home circumstances.

There are three different ways of feeding your child using the gastrostomy:

- **A bolus** – is the required amount of feed given in one go
- **Continuous** – giving the feed slowly over a number of hours using a pump
- **Combination of both**



If the dietician decides that a pump is best for your child, you will require pump training. This will be organised by the dietician and **training** can take place in hospital or at home.

What can we put down the gastrostomy tube?

Your child will have a special milk feed which contains all the nutrients and calories they need. Some children may be able to continue to eat regular food by mouth using the gastrostomy to top up their feeds.

It is important to flush the tube before and after each feed with water. 10 mls of water is usually required but it may be less if your child is not allowed a lot of fluids.

Liquid medicine can also be given by the gastrostomy and flushing before and after is important.

When will I be taught how to deal with a gastrostomy?

The nurses on the ward will start to teach you soon after the operation and they will follow a gastrostomy care pathway. They will teach you how to clean around the tube and how to feed your child through it. There is 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 soon become easier

When can we go home?

You will probably be able to go home after an overnight stay as long as you feel confident and your child is well enough. Sometimes children need to stay longer in hospital especially if there are any wound healing problems or significant pain.

How do I look after the gastrostomy site?

The site needs to be kept clean and dry and the nurses on the ward will show you how to care for it. You should keep your child's gastrostomy site clean by washing it once a day with warm water and then patting it dry with a clean towel. Do not rub as this can make the site sore. This is a good opportunity for you to check that the skin is not sore or infected.

You also need to check the bumper bar to ensure it is the correct fit.

After 4 weeks the bumper bar should be rotated daily and advanced and rotated on a weekly basis. Your community nurse will be able to help with this. If it will not move freely this may indicate the bar is too tight.

How do I look after my child's mouth ?

Your child should continue to brush their teeth twice a day and visit the dentist regularly. Applying soft paraffin helps to keep the lips moist. If your child is on oxygen please ask your nurse for advice as they would not be allowed to use soft paraffin or Vaseline.

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

Sometimes it can leak a little and you need to clean the area with some cotton buds moistened with water. If it carries on leaking and the fluid is yellow/green or has an odour or the skin is red, and irritated, contact your GP or community nurse for advice. Remember to check the bumper bar is not too loose or moving.

If clear fluid or milk leaks from the site in first 72 hours after the operation seek urgent advice from Accident & Emergency Department of the nearest hospital.

Where do I get my supplies from?

Before your child is discharged the nurse looking after your child will make a referral to a district nurse. The district nurse will supply any equipment you need and explain where you can get further supplies. The ward will provide you with enough equipment for seven days.

What should I do about medicine?

Always flush the tube with water before and after giving medicine. Tablets can block the tube, so liquid medicine is best. If you need to give medicines in tablet form make sure they are finely crushed and mixed with water.

Never mix medicines together. Measure each one individually, and always flush with water inbetween medicines.

Can my child have a shower or bath?

Yes, showers are best and long soaks in the bath are best avoided. Always remember to tape the tube out of the way so it does not get caught and pulled out. Make sure that you dry around the site, as any dampness can allow bacteria to breed and develop into an infection.

What about swimming?

You child will be able to go swimming once the gastrostomy site has healed, usually about six weeks after the operation. It is advisable to keep the tube tucked away in the costume, a dressing is not necessary when swimming.

After swimming clean around the tube site with warm water and pat dry.

Can we go on holiday?

It is fine to go on holiday but remember to take extra supplies with you. It may be helpful to take a letter from your doctor explaining your child's medical condition. This will help if you need to seek medical help while away.

What do we do if the tube comes out?

You must go to the hospital immediately. A temporary tube will be inserted that is the same width as the PEG. Only if this does not fit should a smaller tube be inserted, this will need to be done as soon as possible by a member of the casualty staff.

The tube must be replaced as soon as possible (within one hour). Replacing the tube as soon as possible makes it easier to **insert** another tube.

What can I do if my child has wind?

Some parents find that if a child is upset due to wind, putting an empty syringe onto the end of the gastrostomy may help to release the air. This should be done for 5-10 minutes.

Overgranulation

This is a small flap of skin which can be seen growing around the gastrostomy site and is a tissue reaction to foreign material (the gastrostomy). If left untreated it can lead to sore skin and infection. Careful treatment is effective. Your community nurse should be able to help you treat this.

Can my child go to school with a tube?

Yes your child is safe to go to school. It is advisable to speak to your child's school nurse and teacher before your child returns to school. The tube will not affect your child's day however care should be taken when going swimming or doing PE. If your child requires gastrostomy feeds at school your community nurse can advise school.

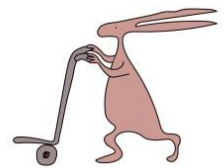
Change from a PEG to a Button feeding device

This is possible after the PEG has been in place for a minimum of six months. An anaesthetic is required to remove the PEG and insert a button. Your child will be admitted as a day case for this procedure

Points to remember

Do

- Wash your hands thoroughly before touching the site.
- Clean and dry around the PEG and under the bar everyday.
- Only put liquids and medicines down the tube.
- Flush before and after every feed (and giving medicines) with water to prevent blockages.
- Check the site daily for redness, swelling or sore skin.
- Ensure the bar is adjusted, **for example** if it is too tight or loose.
- **Remember that if the tube accidentally comes out you must contact the hospital immediately.**
- Seek medical advice if your child has any trauma or if the PEG has been accidentally pulled.
Do not use until it has been tested and is still in position in the stomach.
- Bring any medicines with you to the hospital.
- When the site is healed turn tube 360⁰ everyday. (completely round)



Do not

- Use dressings.
- Close the clamp for long periods of time in one position, as it will damage the tube.

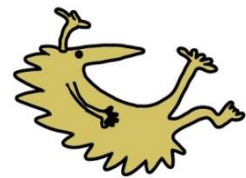
Key points to observe for in the first three days

- If your child starts to vomit green bile.
- If your child is complaining of bad pain (or if not able) is distressed and cannot be comforted. Especially during feeds.
- If your child stomach looks more swollen than normal and is painful to touch.
- If your child's gastrostomy site is leaking fluid/milk.
- If the newly placed gastrostomy tube has fallen out.
- If your child has been vomiting and becomes sunken eyed, stops passing urine or goes floppy.
- If there is fresh bleeding from the site

If your child has any of the above problems do not delay and **take your child to the nearest Accident & Emergency Department**

Contact Numbers

Ward 3A 0151 2525447
Ward 3C 0151 2525701



Stoma Nurse 0151-293 3683: answer machine available.
Working hours are Monday to Friday
8.00 am to 4.00pm

Stoma nurse clinic is now an appointment clinic. Please ring number above to make the appointment. The clinic is every Monday morning except bank holidays

Monday 9.00 am – 12.00 midday. L level 2 Outpatients Dept,

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust
Alder Hey
Eaton Road
Liverpool
L12 2AP

Tel: 0151 228 4811
www.alderhey.nhs.uk

