

Oxford Patient Safety Collaborative Specialised Paediatric Programme

Discharge Training and Information Pack for Parents and Carers

Care and use of your child's PEG Gastrostomy Tube

Child's name	
Date booklet given	
Contact details for your Children's Community Nurse [CCN]	

Type and size of your child's PEG tube:

Contents

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Introduction

This booklet contains important information that you need because your child has been fitted with a Percutaneous Endoscopic Gastrostomy ('PEG') tube.

It also contains a set of competencies which record skills you will be trained in to enable you to care for your child, and advice on where to get help if you have any problems or questions.

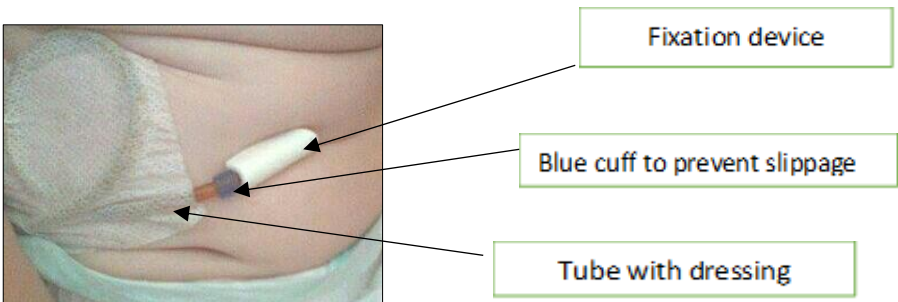
Its aim is to support you so that you can give safe care when your child leaves hospital.

What is a PEG tube and what do they look like?

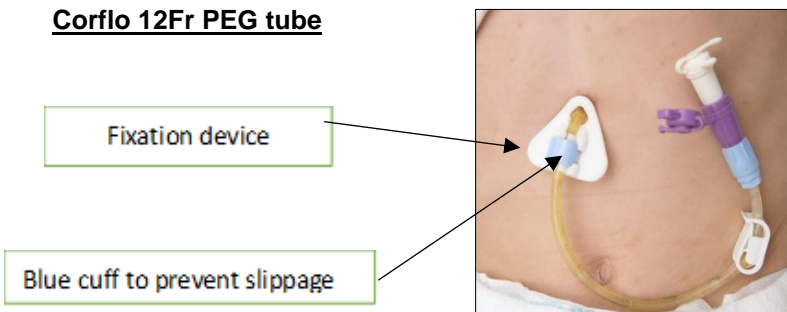
A PEG tube is a feeding tube inserted through the abdominal wall directly into the stomach to provide nutrition and is used when sufficient nutrition cannot be taken in via the mouth.

It is held in place with a retention bolster or disk on the inside of the stomach and a fixation device on the outside, against the skin.

There are different types. The most commonly used devices for children in the Thames Valley Region are: Corflo (12Fr) and Freka (9Fr or 15Fr) PEG tubes



Corflo 12Fr PEG tube



Freka 15Fr PEG tube

Infection Control

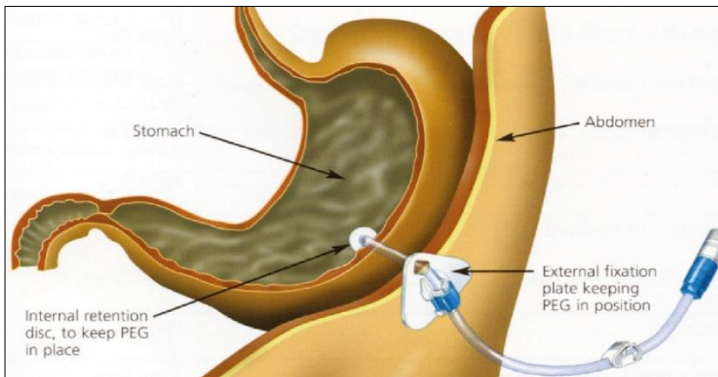
A good hand washing technique is essential before and after caring for a PEG tube. Hand washing for 30 seconds using the technique below ensures your hands are cleaned properly

Hand washing technique



Daily care of the stoma site

PEG tube in situ



The area where the PEG tube enters the stomach is called the stoma site.

- Some discharge from it is normal for the first few days after PEG insertion (see Troubleshooting section on page 8)
- Wash your hands with soap and water using the technique above before and after touching the stoma site, rinse and dry well.
- Before cleaning the site, check for signs of any leakage, redness, swelling, irritation or skin breakdown or if the fixator device looks too loose or too tight. If you think this might be the case, see Troubleshooting section on page 8 or discuss with your CCN who will advise and support you to tighten/loosen it.
- You may need to clean the stoma with cool boiled water and gauze every day for the first few days after PEG insertion. The stoma site will have some discharge and will need to be kept clean to help prevent infection. Dry the area after cleaning.
- Your child can have a bath or shower after 5 to 7 days and the site can be cleaned with mild soap and water once it has healed.
- The tube should be turned daily. The surgical team will advise on when to start this, usually between 2 to 7 days from insertion. Turning the tube can also allow you to clean and reach all the areas around the tube.
- Your child may need the tube secured with tape to prevent it from being pulled. You will be shown how to tape the tube. Some tapes can make the skin red/sore so don't fix the tape to the same area every time. It is advisable to tape the tube above the stoma site (i.e. the end of the tube pointing toward the chest) to prevent stomach contents from moving back into the tube.

Weekly care of the stoma site

- Under supervision of your CCN, the external fixation device can be separated from the base and unclipped after 4 weeks once it has healed. This allows for further cleaning of this part of the device and checking the position of the internal bumper/disk. Your Community Nurse will support you with this but do not loosen the fixation device unless advised by your CCN or doctor.
- **Freka Tube:** Once the tube has been unclipped from the fixation plate, hold the end of the tube and rotate it 360 degrees (a complete

circle). Push the tube 2-3 cm into the stomach and pull it gently back to its original position and secure back to the fixation plate. This will help prevent the internal disk of the PEG tube from becoming buried and the stomach lining growing around it.

- **Corflo Tube:** The fixation device cover can be separated from the base to allow for further cleaning. The tube can then be advanced into the stomach and rotated to prevent the bumper attaching to the stomach wall, gently pull back until you feel the internal bumper against the stomach. Refasten the device which should sit comfortably on the abdomen.

Flushing the PEG tube

Flushing keeps the PEG tube clean and prevents blockages. It should be flushed:

- Before and after each feed
- Before and after each medication
- At least once a day if not in use.

Wash your hands with soap and water before and after flushing, and wear gloves if advised by your CCN.

The tube can be flushed using a 20ml or 60 ml syringe, you will be shown how much water to use.

Use cool boiled water if child is under one year of age, or as advised

Remember do not put anything down the tube other than the recommended feed, water or medication

Administering a feed

- You will be given a feeding plan/regime at discharge, usually by the dietician, so that you know how much feed and water to put down the tube.
- Gather all the equipment you will need:
 - Feed (check that it is in date and not spoiled)
 - Water for flushing tube (cool boiled water if under 1 year or as advised)
 - A clean 20 ml/ 60 ml syringe (sterilised if your child is immune suppressed)
 - Feed pump and feed giving set if your child is pump fed

- Wash your hands with soap and water and dry thoroughly (wear gloves if advised). Wash hands before and after feed.
- Clean the end of the PEG tube (if necessary). Milk can collect at the end so it is important to clean it if there is old milk present. A clean flannel/towel can be used with tap water to do this.
- Make sure that your child is upright during feeding
- Remove the plunger of the syringe and attach it to the PEG tube
- Unclamp and flush the tube slowly with the recommended amount of water, and re-clamp it to prevent any air getting into the tube
- Administer a bolus feed by putting the recommended amount of feed in the syringe, unclamping the tube and holding the syringe upright above the level of the gastrostomy stoma. Give the feed over 15-20 minutes.
- For feeds via a feeding pump, you will be shown how to give the feed by your hospital or CCN.
- After administering feed, flush the tube with the recommended amount of water, this will keep it clean and stop it from blocking.
- After feeding, dispose of the giving set as directed or according to the manufacturer's guidelines.

Re-usable syringes must be washed after every use, dried and stored in a clean area (if child is under one year of age or immunocompromised, follow manufacturer's guidelines).

Follow manufacturer's guidelines on the storage and disposal of the opened feed container.

Administering medication via a PEG tube

- Wash your hands before and after using the PEG tube. Wear gloves if advised.
- Get the medication ready plus water for flushing.
- Flush the tube before and after giving medication, this will keep the tube clean and stop the tube from blocking.
- Medicines should be given separately and flushed with the recommended amount of water each time to prevent any possible interaction.
- It is important not to add the medicine to the feed as it can cause tube blockage.

- Inform your pharmacist and GP that your child has a PEG tube before any new medications are prescribed and dispensed. If medication is in tablet form, ask your pharmacist for advice on how to give the medication via the PEG tube.

Troubleshooting

Serious complications with PEGs are rare, however if you notice any of these symptoms within 72 hours of your child's PEG insertion, seek urgent medical attention:

Red flag symptoms

- Severe pain or distress
- Fresh bleeding from the gastrostomy site
- Leakage of feed

Infection or Sore skin

If you notice any redness, swelling, inflammation or odour from the stoma site, it may be infected, and you should contact your CCN or GP. Sometimes the skin can be red or sore due to a small amount of gastric leakage, if so contact your CCN to check the gastrostomy site and show you how to loosen/tighten the external fixation device as appropriate.

Blocked tube

Try the following:

- Make sure tube is unclamped
- Make sure the tubing is not 'kinked'
- Try to flush the tube in a pumping motion with warm water or fizzy water with the plunger still on but **do not use excessive force.**
- Try and squeeze the tube up and down between two fingers to break down the blockage
- Attach a 60ml syringe to tube and try and draw back any fluid/obstruction which could be blocking tube.
- **Do not force anything down the tube to unblock it**
- Seek advice from your CCN if tube remains blocked.

Feed leakage

If this happens more than 72 hours after tube insertion it could be due to trapped wind, or the external fixator device could be too loose or too tight and not close enough to the skin. Contact your CCN if you are concerned.

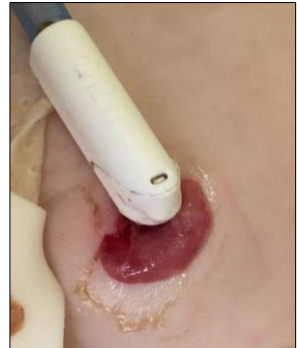
Trapped wind/Venting

Your child may get trapped wind and feel uncomfortable or bloated which can be relieved by 'decompressing' or 'venting' the stomach. This is done by unclamping the tube and attaching a 60 ml syringe without a plunger at least 10cm above abdomen to expel any excess air. This may also help to reduce vomiting by reducing air in the stomach.

Overgranulation

Granulation tissue occurs as the body is trying to heal over the stoma site. You may see pink/raised tissue which may bleed or have a brown discharge. Contact your CCN or GP as your child may need treatment for this.

Overgranulation can also occur if the fixator is too tight or too loose.



Nausea, stomach cramps or vomiting during feeding

This may happen for several reasons:

- Your child may have trapped wind, see venting section above
- The feed may be too cold - always make sure that feed is at room temperature before it is given.
- The feed may be given too quickly - try slowing the rate of feeding.
- If symptoms persist, contact your CCN, dietician or GP.

Diarrhoea

- The rate of feed may need to be slowed down
- If symptoms persist, contact your CCN, dietician or GP.

What to do if the PEG tube comes out

Sometimes a PEG tube may become dislodged or fall out completely, and it is possible for the 'Corflo' PEG tube to be pulled out. If this happens it is important that a new tube is replaced as soon as possible or the stoma will close. You will need to cover the stoma with clean gauze or towel and take your child to your local hospital Emergency Department [ED]. Take the emergency spare tube as well as the old tube with you to the local ED

Ideally the emergency spare tube will be inserted about 3cm into the stoma and taped to secure onto the skin. Alternatively, an "Enplug" or a "Foley" catheter is inserted into the stoma to keep it open.

If the PEG was inserted more than 6 months ago, a balloon device may be inserted by an experienced CCN or member of the medical team. Afterwards, please let your CCN know that a new tube has been inserted.

Replacing the PEG end

The end of the PEG may need replacing if a part has broken or due to general wear and tear.

If this happens contact your CCN who will be able to give you a spare and show you how to attach it.

Frequently asked questions

- **How long does the tube last?**

This depends on the type of tube in place, however if well looked after they can last for a couple of years. You will be able to discuss how long the tube can stay in place for your child with your Consultant.

- **Can my child swim/bath/shower with the tube?**

Yes, once the stoma has healed which is usually 2-3 months after placement. Make sure the tube clamp is closed during this time and that the stoma is dried thoroughly afterwards.

- **Can my child go on holiday or school trips?**

Feeding by tube should not stop your child from going on holiday, however it is a good idea to have a letter from the GP/Consultant as you may need to take feeds and medication with you on the plane.

You will also need to make sure that you have appropriate medical insurance cover, and order sufficient supplies (spare tubes, syringes etc) in advance.

- **What about mouth care?**

Tooth brushing is still important even if your child is being tube fed as plaque can build up quickly. Mouth care is also necessary as sometimes the mouth can become dry. Speak to your child's CCN, speech and language therapist or dentist for advice.

- **What about eating and drinking?**

Although some children are PEG fed as it is not safe for them to eat orally, others are on PEG feeds to supplement their diet if they are not getting sufficient nutrition orally.

If your child has been assessed as being safe to eat and drink by a Speech and Language Therapist or Doctor, having a PEG should not stop them enjoying food or drinks.

If your child has been assessed as having an unsafe swallow, do not give them anything to eat or drink. This could cause harm and put them at risk of choking, or getting food or fluid into their lungs with serious consequences [aspirating]

Managing your child's distress

Your child may find some of the procedures you have to carry out distressing or upsetting. Here are some strategies that may help you to manage in these situations

Preparation

- **Equipment:** Have all the necessary equipment ready in advance, this can help reduce the build-up of anxiety. When equipment is not being used keep it out of sight.
- **Environment:** Wherever possible, avoid carrying out procedures your child finds distressing in areas that you want your child to think of as safe, such as their bedroom.
- **Explain:** If your child is able to understand, explain honestly what needs to be done, why it needs to be done and how it may feel. Avoid giving false reassurances like 'this won't hurt'.

Dolls and story books about children undergoing similar procedures can be helpful when explaining procedures to younger children.

During the procedure

- **Distraction:** Distractions can be useful in reducing distress. You might want to have another person in the room to help with distraction or play some music as this can reduce distress. Younger children in particular may find the use of touch comforting and it can be a good distraction, e.g. holding their hand.
- **Control:** Giving your child a sense of control can reduce feelings of helplessness and uncertainty, e.g. you could get your child to give a signal when they feel ready to start by raising their hand, or let them choose which distraction, activity or incentive they would like to use.
 - **Parental distress:** If you look distressed as the parent, this is likely to impact on your child's anxiety. Give yourself a few minutes to run through the procedure in your head and try to keep calm in front of your child.
 - **Language:** Try to avoid using negatives such as 'don't move'. Saying 'this is the time to hold still' is much more supportive.
 - **Praise:** Use phrases such as 'well done' and 'you're doing great' to help reassure your child.
 - **Breathing:** Breathing techniques can help reduce your child's anxiety. Games like pretending to blow bubbles or pretending to blow the candles out on a cake can help your child to slow their breathing down.
 - **Relaxing:** Your child may find relaxation techniques like pretending to be a rag doll helpful. Holding your child in a comfortable position can be helpful.

What if my child is too distressed to do the procedure?

If your child is so distressed that it is not possible to do the procedure, stay calm and give yourself and your child some time out. Praise your child for what they have managed to do and if you are able to, try to do the procedure later in the day – just because something hasn't worked on one occasion, don't rule it out for the future.

If you need further support, your CCN should be able to help you with the procedure. If you continue to experience problems, ask to be put in

contact with a play therapist who can work with your child to reduce their anxiety.

Looking after yourself

Managing your own emotions

Providing medical care for your child can be emotionally draining for you as the parent. It is important for you to know that you are not alone. Many parents feel anxious and stressed particularly when they are learning to do a new procedure for their child.

Below is some advice from other parents:

- **Ask questions:** Ask lots of questions of your healthcare professionals and take your time learning. If you're not confident carrying out a procedure, ask for more opportunities to practice under supervision. Don't be afraid to ask for more support.
- **Share your feelings:** Explain how you're feeling when people ask. It is normal to feel anxious.
- **Look after yourself:** It does get easier and you will feel overwhelmed at times. Looking after yourself is just as important as looking after your child.
- **Trust your instincts:** You know your child better than anyone else. Never feel bad questioning the "experts".
- **Talk to other families:** It can be really helpful to talk to other parents in similar situations, this can be done in person or online such as through Facebook groups, although advice from these sources can be conflicting and should always be checked with your CCN.

Here are some charities that can also provide helpful information:

- PINNT
<https://pinnt.com/Home.aspx>
- TOFS
<https://www.tofs.org.uk/home.aspx>
- WellChild
<https://www.wellchild.org.uk/>
- ROSY
<http://www.rosy.org.uk/>

PEG Competencies for parents/carers

Child's name	
Date of birth	
Learner's name	
Name of professional undertaking training	

For each skill described in the table below, the Learner [L] and Trainer [T] must each initial the appropriate columns to record training given and competency achieved.

When all the skills are signed off, the Learner should sign the declaration at the end.

Skills: appropriate knowledge and practical demonstration required	Date shown/ discussed		Date practiced		Dates practiced		Learner is confident and safe to deliver care	
	L	T	L	T	L	T	L	Assessor
Anatomy of the digestive system								
Hand washing technique								
Preparing and setting up feed								
Clamping and unclamping tube								
Venting								
Tube flushing								
Feeding: connecting, giving (bolus or pump) and following feeding regime								
Giving medicines								

Skill	Date shown/ discussed		Dates practiced		Dates practiced		Learner is confident and safe to deliver care	
	L	T	L	T	L	T	L	Assessor
Daily and weekly care of tube								
Supplies and equipment required (i.e. emergency spare tube/syringes)								
Cleaning and Storage of Equipment								
Actions in the event of PEG unexpectedly dislodging								
Pump alarms/ Troubleshooting								

Learner's declaration

I believe I am competent and am willing to take on these tasks.

If I feel I need additional support at any time, I will seek advice from the relevant Healthcare Professional:

Learner's name and signature(s):

Date:

This booklet was originally produced by the Children's Community Nursing Team, Oxford Health NHS Foundation Trust.

It has been further developed as part of a partnership project led by the Oxford Academic Health Science Network Patient Safety Collaborative to improve the safety of children with complex medical needs who are technologically dependent and cared for by their families in the community.

In addition to the Oxford Health CCN team, parents of children with gastrostomies and healthcare professionals from the following Trusts and organisations have been involved in compiling and reviewing it:

Berkshire Healthcare NHS Foundation Trust

Buckinghamshire Healthcare NHS Trust

Central and North West London NHS Foundation Trust

Frimley Health NHS Foundation Trust

Great Western Hospitals NHS Foundation Trust

Milton Keynes University Hospital NHS Foundation Trust

Oxford University Hospitals NHS Foundation Trust

Royal Berkshire NHS Foundation Trust

Helen and Douglas House