

Patient Information for Consent



Belfast Health and
Social Care Trust

PS18 PEG (child)

Expires end of June 2020

Local information

Barbour Ward (in-patients)
(028) 9063 3392 or (028) 9063 3398

**Knox Ward/Day Care Unit/pre-admission unit
on**
(028) 9063 3249 or (028) 9063 8182

You can also get information locally from your
consultant's secretary.

Mr Bill McCallion, Consultant Paediatric
Surgeon - (028) 9063 2004

Miss Majella McCullagh, Consultant Paediatric
Surgeon - (028) 9063 2159

Mr Alan Bailie, Consultant Paediatric Surgeon/
Urologist - (028) 9063 2008

Mr Alistair Dick, Consultant Paediatric Surgeon
- (028) 9063 2159

Mr David Marshall, Consultant Paediatric
Surgeon/Urologist - (028) 9063 2008

Mr Isaac Philip, Consultant Paediatric Surgeon -
(028) 9063 2004

Miss Irene Milliken, Consultant Paediatric
Surgeon - (028) 9063 2004

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What is a PEG?

A percutaneous endoscopic gastrostomy (PEG) is an operation to insert a feeding tube through the skin and into your child's stomach (see figure 1).

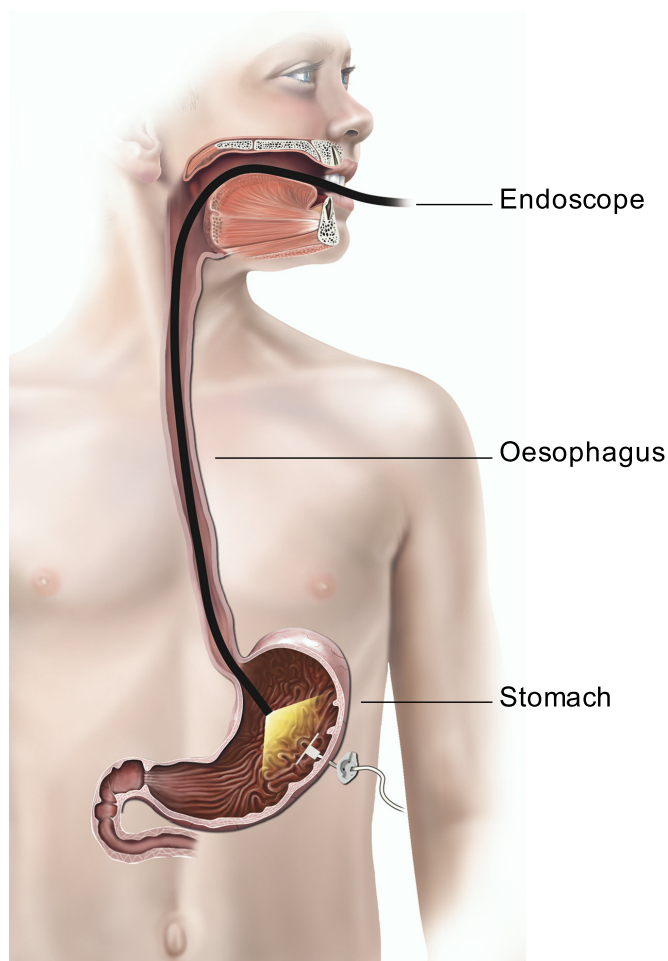


Figure 1
A feeding tube in the stomach

Your doctor has recommended a PEG for your child. This document will give you information about the benefits and risks to help you to be involved in the decision. If you think your child is mature enough, it is best to discuss the operation with them so they can be involved in the decision too.

If you have any questions that this document does not answer, ask your doctor or the healthcare team.

What are the benefits of surgery?

The healthcare team is concerned that your child is not able to eat or drink enough in the normal way. This is usually caused by a problem that makes it difficult for your child to swallow.

A PEG should allow the healthcare team to give your child nutrients and fluid directly into their stomach. They can also give your child medication through the tube.

A PEG will help your child if they have a condition, such as cystic fibrosis, that increases the amount of nutrients they need to maintain their energy levels.

Are there any alternatives to a PEG?

It is possible for the healthcare team to give your child nutrients and fluid through a tube (nasogastric or NG tube) that is placed in their nostrils and down into their stomach. However, an NG tube is suitable only if your child needs help for a short time (less than 3 to 4 weeks). If your child needs help for longer than 3 to 4 weeks, your doctor will usually recommend a PEG or a primary gastrostomy button.

A primary gastrostomy button is a feeding device that can be inserted in your child's stomach using keyhole surgery. The device is inserted through small cuts on the abdominal and stomach walls. The gastrostomy button is attached to a balloon that sits inside the stomach to help prevent the button from falling out.

It is also possible for the healthcare team to give your child nutrients and fluid directly into their bloodstream (total parenteral nutrition – TPN). However, TPN has more possible complications and is usually recommended only if your child cannot take food through their digestive system.

Your doctor will tell you why a PEG has been recommended for your child.

What will happen if I decide that my child will not have the operation?

Your doctor may be able to recommend another way of feeding your child. However, if a PEG is the only dependable way to give your child fluid and nutrients, your child may lose weight and not be able to fight infections as easily. It is important that you discuss this decision carefully with your doctor.

What does the operation involve?

The healthcare team will carry out a number of checks to make sure your child has the operation they came in for. You can help by confirming to your surgeon and the healthcare team your child's name and the operation they are having.

The operation is performed under a general anaesthetic and usually takes about 30 minutes. Your child may also have injections of local anaesthetic to help with the pain after the operation.

Your child may be given antibiotics during the operation to reduce the risk of infection. The operation is usually performed by two surgeons.

One surgeon will place a flexible telescope (endoscope) into the back of your child's throat and down into their stomach. The endoscope will be used to blow air into your child's stomach to improve the view and to expand the stomach so that it presses against the abdominal wall.

The other surgeon will insert a rigid telescope (laparoscope) into your child's abdomen through a small cut made around the umbilicus (belly button). They will find the stomach and then make a small cut on your child's abdominal wall so they can insert a hollow needle into their stomach. They will pass a fine wire through the needle and into the stomach.

The first surgeon will use the endoscope to get hold of the end of the wire and bring it out of your child's mouth. They will attach the feeding tube to the wire.

The other surgeon will use the wire to pull the tube down into your child's stomach. They will use the needle as a guide while they bring the wire and tube out of your child's stomach and through the hole in their abdominal wall (exit site). The surgeon will remove the needle to leave one end of the feeding tube in your child's stomach with about 8 to 10 centimetres of tube outside of the abdomen.

The tube has a bolster (cross-piece or internal flange) that sits inside your child's stomach and helps to prevent the tube from coming out. Over the next few months the stomach and abdominal wall will join together.

What complications can happen?

The healthcare team will try to reduce the risk of complications.

Any numbers which relate to risk are from studies of people who have had this operation. Your doctor may be able to tell you if the risk of a complication is higher or lower for your child.

Some complications can be serious and can even cause death.

You should ask your doctor if there is anything you do not understand.

Your anaesthetist will be able to discuss with you the possible complications of having an anaesthetic.

General complications of any operation

- **Pain.** The healthcare team will give your child medication to control the pain.
- **Bleeding during or after the operation.** This is rare and can usually be stopped by using a dressing to put pressure on the wound.
- **Unsightly scarring of the skin.** The risk is higher if the exit site becomes infected. The scar will usually be less noticeable when your child has grown up.
- **Infection.** Any infection is usually mild and affects only the area around the exit site (risk: 1 in 10). The tissues of the abdomen can get infected (risk: 1 in 1,000). Your doctor may give your child antibiotics to reduce this risk. It is possible to get an infection from the equipment used, or if bacteria enter your child's blood. The equipment is disinfected so the risk is low but let the endoscopist know if your child has a heart abnormality or a weak immune system. Your child may need treatment with antibiotics. Let your doctor know if your child gets a high temperature or feels unwell.

Specific early complications

- **Damage to teeth.** Your surgeon will place a plastic mouthpiece in your child's mouth to help protect their teeth. Let your surgeon know if your child has any loose teeth.

- Allergic reaction to the equipment, materials or medication. The healthcare team is trained to detect and treat any reactions that might happen. Let your surgeon know if your child has any allergies or if they have reacted to any medication or tests in the past.
- Damage to the liver or intestine, if the liver or intestine is stuck close to the stomach as a result of previous surgery (risk: less than 1 in 500). This can be life-threatening.
- Inflammation of the lining of the abdomen (peritonitis), if some air or bowel contents leak into the abdominal cavity. Your child may need another operation to close the leak. Peritonitis can usually be treated with antibiotics and usually settles within 2 to 3 days. The healthcare team may need to delay feeding your child using the PEG tube.
- PEG tube falling out before the stomach heals properly to the abdominal wall. This is serious. Do not try to put the tube back. Do not feed your child. Call an ambulance or go immediately to your nearest Emergency department.

Specific late complications

- Tissue granulation around the exit site. It is normal for a small amount of moist connective tissue, dark pink or red in colour, to develop around the PEG tube as the body tries to heal the wound but a lot of tissue can cause pain and make it difficult to care for the tube. Follow your doctor's advice about using silver nitrate to treat the tissue.
- Prolapse, where the lining of the stomach pushes through the exit site. Your child may need surgery if the prolapse gets too big.
- Blocked PEG tube. This can happen at any time but usually happens after a number of months as the tube deteriorates. The tube usually needs to be replaced with a gastrostomy button or another PEG tube after 18 months.
- Leaking from the exit site, if the hole in the stomach gets larger than the tube. Sometimes the healthcare team will need to remove the tube for up to a few days to allow the hole to get smaller. Your child will usually need a gastrostomy button.

- Developing gastro-oesophageal reflux (acid reflux), where acid from the stomach travels up into the oesophagus (gullet). The risk is higher in children with neurological disorders such as cerebral palsy. Simple measures, such as giving smaller feeds more often and breastfeeding your child in an upright position, are often all that you need to do. If your child does not respond, they can be given medication to control the symptoms. If the symptoms continue, your surgeon may recommend an operation to prevent the acid from travelling into your child's oesophagus.

How soon will my child recover?

In hospital

After the procedure your child will be transferred to the recovery area and then to the ward.

Your child may feel a bit bloated for a few hours but this will pass. They will usually have a tight feeling in the area where the PEG tube is. This settles within 1 to 2 days.

You (or your child's carer) will usually be trained by a specialist nurse or dietician who will show you how to feed your child using the PEG tube and how to prevent any infection. It is important to follow the advice you are given.

If you are worried about anything, in hospital or at home, contact the healthcare team. They should be able to reassure you or identify and treat any complications.

Returning to normal activities

If your child has a lot of pain when feeding, bleeding or leaking from the exit site within 3 days of having the feeding tube, it is important that they stop feeding and you contact the healthcare team.

Depending on the problem that made it difficult for your child to swallow, your child should be able to return to normal activities after 1 to 2 weeks.

If your child wants to swim, use a waterproof dressing.

If you have any problems with the PEG tube or exit site, contact the healthcare team. In an emergency, call an ambulance or go immediately to your nearest Emergency department.

The future

The healthcare team will monitor your child closely. Your doctor will advise you on how long your child needs to have the PEG tube. This will depend on the problem that made it difficult for your child to swallow.

If your child needs a PEG tube for more than 18 months, your doctor will discuss with you about replacing the tube with a gastrostomy button.

Once the PEG tube is removed, the hole in the stomach may leak for a few days but then usually heals by itself. If the hole does not heal properly, contents of the stomach can leak onto the skin (gastrocutaneous fistula). This is more likely if the PEG tube has been in place for longer than 8 months. Your child may need another operation.

Summary

If your child is not able to eat and drink enough in the normal way, a PEG tube should allow your child to get the nutrients and fluid they need for healthy growth and development.

Surgery is usually safe and effective but complications can happen. You need to know about them to help you to make an informed decision about surgery for your child. Knowing about them will also help you to help the healthcare team to detect and treat any problems early.

Keep this information document. Use it to help you if you need to talk to the healthcare team.

Acknowledgements

Reviewer: Mr Shailinder Singh DM FRCS (Paed. Surg.)

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This document is intended for information purposes only and should not replace advice that your relevant healthcare team would give you.