Patient Information

Royal Devon University Healthcare NHS Foundation Trust

Percutaneous Endoscopic Gastrostomy (PEG)

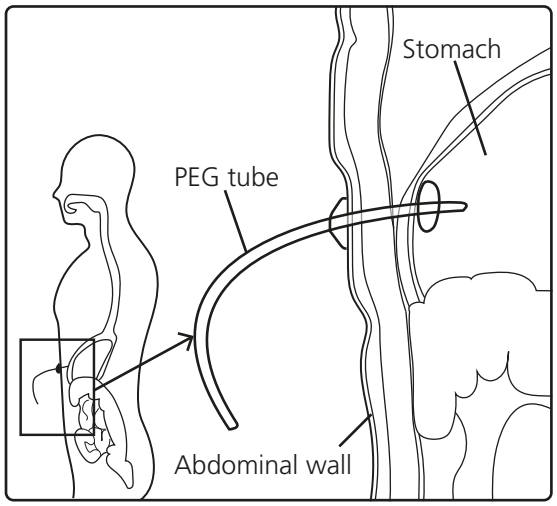
This leaflet is intended to help you and your relatives, or carers, understand more about a gastrostomy. It will explain how and why gastrostomy tubes are placed, and the risks and benefits of them. This leaflet will focus on a percutaneous endoscopic gastrostomy (PEG). For the purposes of this information will be referred to as PEG.

There is a lot of information to read. You may want to show your carers or relatives this leaflet to help them understand the decisions you need to make.

You should keep this information leaflet in a safe place. If your care givers change it will help them to be able to read about your PEG.

What is a gastrostomy?

Gastrostomy is the word used to describe an artificial opening into the stomach, usually from the surface of the abdomen. A narrow flexible feeding tube will be used to create a channel to the stomach. It will allow liquid food, medicines and water to be fed directly into the stomach.



Why do I need a PEG?

Gastrostomy tubes are used for people who cannot eat and/or drink properly. This may be for a variety of reasons such as, but not limited to:

- **Head injury, brain haemorrhage, brain tumour, and stroke:** you may be unconscious or too drowsy to eat and drink properly or your illness may have affected your ability to swallow properly. This can be temporary or permanent. Adequate nutrition (food) and hydration (fluid) is an important aid to recovering from illness or injury. In the early stages of illness or injury it is possible to provide enough nutrition and hydration with an intravenous drip. Later, a nasogastric tube feeding tube (NG) may be placed to allow you further time to recover. If an NG tube is tolerated well, it can stay in for a number of weeks before a PEG is considered.
- **Progressive degenerative disease such Motor Neurone Disease, Multiple Sclerosis, non-specific muscular atrophy:** disease progression may mean you lose the ability to swallow. Placing a PEG provides adequate nutrition and hydration whilst allowing you to continue enjoying your daily activities.
- **Prior to planned treatment:** where treatment for another disease is expected to affect your ability to swallow or desire to eat such as radiotherapy or chemotherapy a PEG is sometimes placed.

Why is a swallow reflex important?

The swallow and cough reflex are complex mechanisms that are closely linked. They act as a protective mechanism for your airway. If you lose the ability to swallow properly your ability to cough will also be affected. Eating and drinking may make you cough because food and liquids are going down the wrong way but your cough is not strong enough to expel the food or drink. This is called aspirating and every time this happens you are at risk of developing aspiration pneumonia.

Will I be able to eat and drink with a PEG?

Your speech and language therapist will have assessed your swallow and will be able to advise you what, if anything, is safe to eat or drink. Having a PEG will not affect this and you can continue eating and drinking the things you can currently manage.

How long will I need the PEG?

The PEG can be removed if or when it is no longer needed. Your dietitian or doctor will be able to advise you if they think the tube can be removed. If this is the case, they will write to the nutrition team and ask us to arrange removal for you. You will need another gastroscopy to have it removed.

How long does a PEG last?

With good care and management PEGs can last on average up to three years. Sometimes they can last longer. If you need a PEG permanently your community nurses, carers or dietitian will monitor it for signs of deterioration. Often the first sign of it needing to be changed is if it starts to leak around the site when used. You will need a gastroscopy to have it replaced.

What happens before the procedure?

You will need a gastroscopy to have the PEG placed. If you are an outpatient please refer to the Gastroscopy (OGD) leaflet that was sent with your appointment details.

If you are an inpatient the ward nursing staff will ensure you are prepared properly for the procedure.

In both cases you will need a blood test a day or so before.

How is the PEG inserted?

You will need a gastroscopy to have the PEG placed. You will have been assessed as to whether you are suitable for sedation or throat spray.

The endoscope will be placed into your mouth, past your throat andinto your stomach. This allows us to see inside your stomach and to choose a suitable site for the PEG tube.

Local anaesthetic will be injected into the skin of the abdomen at the place where the PEG will be placed. This is to numb the area. A small cut is made into the skin of your abdomen. The PEG is then pulled back through this. The wires are then cut and the PEG is secured.. The PEG is secured on the inside by a flat bumper (an internal flange)And secured externally using some simple attachments.

The procedure usually takes about 20-30 minutes. Your breathing and heart rate will be monitored throughout the procedure.

The procedure should not be painful, but may be a little uncomfortable at times. You may have been assessed as requiring a general anaesthetic, in which case, you will not be aware of anything until after the procedure.

What happens after the procedure?

After the procedure you will be taken to a recovery area and looked after by a nurse until you have fully recovered from the sedation or general anaesthetic. If you are already an in-patient, you will then be taken back to your ward.

If you are an outpatient, who arrived from home, you will stay in the endoscopy department until a bed on the wards is available. The ward will be expecting you but a bed may not be available until sometime after your procedure.

If this is the case, it would not be unusual to spend the time waiting in a bed in the endoscopy unit. The nurses in the endoscopy unit will ensure you are comfortable. Arrangements can be made for a spouse or relative to be with you if that is what you want.

How long will I stay in hospital?

You will be asked to come in either on the day of your procedure or the day before.

You should prepare for a stay of at least three days following your procedure.

How will I use my PEG tube?

During the clinic or bedside assessment you will be shown what a PEG looks like. You will have the opportunity to handle it and we will discuss how you use it. It is best if you bring a family member, friend or carer with you to this appointment. You will be provided with written information and given the opportunity to ask questions.

If you decide to go ahead with the PEG you will be shown how to use it before being discharged from hospital.

Fitness for the procedure

When you or your doctor has decided this is the right course of action for you, you will need to be assessed to determine your fitness to undergo the procedure. If you are a patient in the hospital we will come to your bedside to do this. If you are a patient living at home or in a care facility we will invite you to an outpatient appointment.

To help us work out if you are fit enough for the procedure you may need a lung function test. If this is the case we will try to arrange the appointment for the same day as the assessment appointment.

Decision making and consent

We want you to have an informed decision as to whether you want the PEG placed. We recognize that this can be a difficult decision, and that it sometimes needs to be made at a time when you least want to think about it. Understanding the benefits and risks at an early stage will help you come to a decision that is right for you.

It is important that you fully understand your proposed treatment, any possible alternatives and the possible risks so that you can decide for yourself whether to proceed with the PEG. You have the right to refuse any suggested examinations, tests or treatment if you feel this is not the best option for you. You can only make an informed decision if you are fully aware about why a PEG has been recommended and any consequences relating to the procedure.

Alternatives

- You may choose not to have a PEG.
- Your doctor or nurse may decide that a different type of gastrostomy or a different feeding method is the safest option for you. If this is the case then your doctor or nutrition nurse will discuss alternatives and the reasons why. Separate information will be provided.

Complications and Risks

Gastroscopy with PEG insertion is generally considered a safe procedure and serious complications are rare. Even so, no treatment or procedure is totally risk free. Your doctor may have recommended this for you but you should be aware of the risks and complications to help you decide if this is right for you.

Pain

Afterwards you may experience some slight discomfort or tenderness. This is normal and you can ask the nurse for pain relief if you need it. Excessive pain when using the tube is unusual and may indicate a complication. Pain or discomfort for a longer period of time even after discharge should prompt you to seek advice from a health care professional.

You may experience a sore throat afterwards from the gastroscopy part of the procedure.

Bleeding

A small amount of oozing at the wound site is normal. Sometimes, however the bleeding can be more noticeable. This will usually stop of its own accord, but do inform the nursing staff who will monitor it.

Some internal bleeding is to be expected from the puncture site and again will usually stop of its own accord. Rarely a tear in another part of the gullet or stomach caused by the gastroscope can bleed. Again this should stop of its own accord.

If you take blood thinning drugs these will be stopped or altered prior to your procedure under the direction of your medical team.

A small number of cases (1%) need to be taken to theatre to stop the bleeding.

Wound Infection

An infection can occur after the insertion of the PEG. Standard antibiotics will be given at the time of insertion. However, despite this around 5-25% of patients will get an infection. Wound infections are usually confined to the skin site, but may occasionally cause a more serious illness.

Overgranulation

Overgranulation is often described as a small amount of extra pink tissue growing at the insertion site. It can be sore and bleed a little on contact. On the whole, it will not cause you any harm but it is best to try to minimize the overgranulation. This is a not an uncommon complication of PEG insertion and can occur at any time after insertion. It happens because the human body recognizes the tube as a foreign body and will try to grow extra tissue to protect itself. Treatment usually consists of a course of low dose hydrocortisone cream and pressure dressings. If you are prone to overgranulation it may recur from time to time even after treatment.

Leakage

Sometimes feed can leak out around the PEG site. This can happen straight away or much later. If you start to experience leakage you should inform your community dietetic service who can visit and assess why this might be happening.

Buried bumper

The internal flange of the PEG sits snuggly against the underside of the stomach. Failure to provide appropriate and regular care and maintenance to the PEG can result in the internal flange, or bumper, becoming buried in the wall of the stomach. This happens because the lining of the stomach recognises the flange as a foreign body and tries to grow over it. Eventually the flange becomes entirely covered and the hole at the end of the tube, where the feed enters the stomach will become blocked. In this instance an operation will be required to remove and replace the PEG.

Due to the high vulnerability of patients needing a PEG it is good practice to maintain a rigorous ‘advance and rotate’ process to avoid unnecessary surgery.

Damage to another organ or perforation

There is a 1% chance the liver can be caught during the PEG insertion process. This very much depends on your anatomy and can be difficult to predict before the procedure. To minimize this we may arrange for some patients to have an ultrasound scan just before or during the procedure to help define the anatomy.

A tear or perforation of the gullet from the gastroscopy is rare, about 0.1%. Damage to the bowel is a potential risk due to the nature of the insertion of the PEG. Safety checks will be performed before the procedure to minimize this risk but it can still occur. It may not be possible to diagnose this at the time of the procedure as the symptoms usually present later with abdominal pain.

Damage to the colon and small bowel is rare in adults but can occur at a rate of 2-3.5% in children.

Rarely damage can occur to teeth and/or bridgework from the gastroscopy part of the procedure.

Tube displacement

After the PEG is inserted there is a risk of it becoming displaced, meaning it has moved from where it was initially placed. The main cause of this is if the PEG is put under a lot of tension or extreme movement in the first 3-4 weeks. The main symptom is pain on feeding or flushing. You or the nursing staff should stop any infusions or feed and inform a doctor. An X-ray of the tube will take place and depending on the results the tube may need to be removed completely or replaced.

Malposition of PEG

Malposition is when the gastrostomy tube, or part of the tube, is placed in an organ other than the stomach. This can include the small bowel, large bowel, abdominal cavity or abdominal wall. This is extremely rare with only a few recorded cases in the literature. However, rarely it can occur acutely while placing the tube. As explained above, a needle is placed into the abdominal wall. This is intended to pass into the stomach. However, when passing the needle through the abdominal wall into the stomach, rarely there is a loop of small or large bowel between the abdominal wall and the stomach. Therefore, this loop can get caught by the needle. As a result, the PEG will be inserted through the bowel wall (small or large) into the stomach. This can cause immediate problems with leakage and peritonitis (see above). It would be important to assess this carefully at the time as removing the tube at that stage is not always the best solution. If the tube is required to be removed, this may need to be through an operation. However, it is possible that this can happen and cause no symptoms or any problems. If the PEG is then used for more than 4 to 6 weeks as planned, this can cause the tract to become well formed and mature and cause no further problems. It could be then used as normal.

Peritonitis

Up to 2.3% of patients can be affected by peritonitis which occurs when bacteria crosses the puncture site and causes severe inflammation inside the abdominal cavity.

Chemical peritonitis is when feed or medicines enter the abdominal cavity from a displaced tube. It carries a high death rate. Antibiotics will be given during the procedure to reduce the risk.

Sedation and General Anaesthetic

Sedation or an anaesthetic can affect your breathing during and/or after the procedure. Around 1% of patients are affected by aspiration pneumonia from having the PEG placed. For this reason if you have a chest infection we may decide to postpone the PEG until your infection has cleared.

Your disease may have affected your chest and breathing muscles and we may arrange a lung function test to help us decide how best to proceed.

Mortality

The procedure itself carries a small risk of death (<1%). However, patients who require PEG insertion are often very frail with other serious medical problems. Up to 25% of patients will die within 3 months of PEG insertion because of their other medical problems.

Sometimes we recommend that an individual is not fit enough to undergo the procedure.

Failure to place the tube

Occasionally we discover at the time of PEG insertion that it is not possible to insert the PEG safely. In this instance the procedure will be abandoned. Once you are fully awake the doctor and nutrition nurse will explain what has happened and any possible alternative options.

Who looks after the PEG?

For most people we expect that you or a spouse or relative will be able to look after the PEG. Before the PEG is placed you will have received a lot of information both written and verbal about how to look after it. This will help you to decide if you think you can manage it yourself or if you need assistance.

A separate information leaflet is provided for you to refer to when learning how to look after your PEG. During the discussion period before, and

afterwards on the ward you will also be given instruction and practice to use the PEG. Once at home your community dietician will provide support and advice.

Normally, the district nurses are not able to provide any support with looking after a PEG. If you or we think that you will not manage, then a package of care will need to be arranged. This may mean that carers from a care agency will visit twice a day to connect and disconnect your feed. Often we will not place a PEG until all the support at home is in place.

Sometimes it is difficult to find a care agency that can provide the appropriate level of skill and care required. If you already have carers they may not be able to provide the additional care required for your PEG. Rarely, if no suitable care agency can be found in your locality, then you may have to enter a care home after having your PEG.

If you already reside in a care facility then the staff there will be able to look after the PEG for you.

It is better to decide who is going to look after the PEG before it is placed. Failure to do this can result in a delayed discharge from hospital

Any other questions?

We hope that this leaflet has answers some of the questions you may have. Please feel free to ask any questions you may have and remember that no question is ever too silly. If you have any further queries or require any further information please do not hesitate to get in touch.

- For questions and queries about information you have been given before your PEG placement. The Nutrition Support Team is available between 8am and 4pm Monday to Friday. If calls are not answered by a member of the nutrition team please leave a message. Messages are picked up three times a day.

  Nutrition Support Team.....01392 404635

- For questions and queries when you are at home the community dietician can help. They are available between 9am and 4pm Monday to Friday.

  Community Dietician.....01392 403555

- For urgent queries concerns or queries that cannot wait, or you have tried contacting the above numbers then please use the following service

  Urgent queries.....111

If you would like to find out more about PEG feeding the following websites may be helpful. Just type PEG into the search box.

- **www.patient.co.uk**
- **www.bsg.org.uk**
- **www.mndassociation.org**
- **www.mstrust.org.uk**

PLEASE KEEP THIS LEAFLET SAFE. YOU MAY NEED TO REFER TO IT FROM TIME TO TIME.

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