

# **Gastrostomy tube placement**

Every patient who receives this booklet must also have access to a health care professional to talk to about this decision.

## Information for patients and care

This booklet is designed to help you and your relatives/carers understand more about gastrostomy tubes, including why they are used, and the procedures involved in their placement. A member of staff will answer any questions that you may have, so as you are reading through the booklet you may want to make a note of questions that you wish to ask.

#### What is a gastrostomy?

A gastrostomy is a thin flexible tube that passes through the skin of the abdomen and into the stomach. It allows liquid food and water to be fed directly into the stomach.

#### Why do I need one?

You may need a gastrostomy tube because you are unable to eat or drink enough (or even at all) and it is therefore not possible to meet your nutritional needs without one. Sometimes a gastrostomy tube is placed in advance because a particular treatment is known to cause problems with eating or drinking, or team members predict that you will be unlikely to eat or drink enough due to your illness.

If you decide that you do not wish to have a tube, it may mean you are unable to maintain your nutrition and hydration needs. It may also affect your ability to cope with your medical treatment. However, remember that it is your choice not anyone else's and we will support you as best we can, even if you decide that you do not want a gastrostomy tube.

#### Alternatives to Gastrostomy What are my other options if I decide not to have one?

If you decide you do not want to have a gastrostomy there may be another alternative, but this will depend on your medical condition and the reasons why you are being fed. Please ask the member of staff who gave you this booklet to discuss other options with you.

You may decide that you do not wish to be tube fed at all. If this is what you really want you will be supported in this decision, but you will need to have discussed it fully with your doctor and other members of the multidisciplinary team so that you are clear about what it means for you.

## Will are gastrostomy tube stop me from eating and drinking?

No. Provided you have been told that you can eat and drink having the tube will make no difference.

However, there are times when it will be recommended that you do not eat and drink by mouth. In these cases, a Speech and Language Therapist will be involved in your care and will advise on what is recommended for you.

Changing how we eat has an impact on how we live our lives. You may appreciate and value being able to get all your nutrition through a tube, but you may also find that the changes impact your emotions, causing feelings of sadness or loss. Sharing how you feel with your health care team is important, so please let us know.

## How is the procedure done, how will it be put into my stomach?

There are three different ways of inserting gastrostomy tubes, but they all have the same result. The different names describe the method of insertion.

- A surgical gastrostomy is one that is placed during an operation.
- A Percutaneous Endoscopic Gastrostomy (PEG) is a procedure that uses an endoscope (a flexible tube that is passed into your stomach).
- A Radiological Inserted Gastrostomy (RIG) is one that is done under x-ray.

The type of gastrostomy that you will receive will be fully discussed with you, but if you have any further questions, please feel free to ask a member of the team.

#### What happens before your procedure?

Gastrostomy tubes are normally placed whilst you are in hospital, but they can be arranged as a day case, with plans for you to only be in hospital for 8-10 hours. In either case, a few days before the procedure you will have a blood test and the nutrition nurse or dietitian will contact you and fully explain your procedure to you.

If you come into hospital on the day the tube is to be placed, then most of these things will take place on the morning of the procedure. In most cases you will be given an antibiotic through a small needle in the back of your hand or lower arm. You will be instructed not to eat or drink anything for six hours before the procedure. The nursing staff will remind you about this.

We will then take you on your bed or hospital trolley to theatre or endoscopy unit (if you are having a PEG) or radiology (if you are having a RIG) where you will be greeted by one of the staff. We will try to perform the procedure as promptly as possible but sometimes you may have to wait a while.

We will then ask you to remove any false teeth and oxygen tubing will be placed under your nose to help your breathing. The nurse will also place a blood pressure cuff on your arm and oxygen monitor on your finger.

The doctor carrying out the procedure will check your consent form with you.

If you are having a PEG tube a mouth guard will be placed between your teeth and you will then be given you some sedation.

If you are having a RIG tube a small tube will be passed through your mouth or nose into your stomach. In some cases, this tube may already be in place. If previously agreed you will then be given some sedation.

Sedation is not the same as a general anaesthetic, but it will make you feel relaxed and drowsy. Your pulse and blood pressure will also be monitored, and you would be given oxygen.

If you are having a surgical gastrostomy an anaesthetist, you will give you a general anaesthetic.

#### The consent form

We must be sure that you agree to what is being proposed for you and the consent form must be signed before we can proceed. Before signing you should be satisfied that you have been given all the information that you require. You are entitled to change your mind at any time even after you have signed the form.

Please read it through carefully and if you are satisfied that you understand it you can then sign the form. You can sign on the day of the procedure if you wish. Please ask if there is anything you don't understand.

If this procedure is being considered for a patient who cannot give consent; cannot understand the decision, weigh up consequences, or communicate their wishes, then it is the responsibility of the Consultant to make a decision that is in the best interests of the patient. This decision will be made with the health care staff involved in caring for the patient, as well as the patient's family members.

#### What happens during the procedure? If you are having a PEG

You are given a local anaesthetic to numb the area on your stomach where the tube is inserted. An endoscope (a flexible tube with a light and camera at one end) is then passed through your mouth into the back of your throat and down into your stomach. A small cut is made in the skin on your abdomen and the PEG tube is then passed through. Finally, a dressing is placed over the site. The whole procedure usually takes 15 to 20 minutes from start to finish.





#### If you are having a RIG

Sedation is not usually used but can be discussed with the Radiologist carrying out the procedure. A small flexible tube, called a nasogastric tube, is passed through your nose into the back of your throat and down into your stomach. This is used to fill your stomach with air.

You will be given a local anaesthetic to numb the area on your stomach where the tube will be inserted. X-ray images will be used to guide the procedure. Two or three sutures will be put into your stomach and then a small cut is made in the skin on your abdomen and the tube passed through. Finally, a dressing his placed over the site. The whole procedure usually takes about 20 to 30 minutes from start to finish.



#### If you are having a surgical gastrostomy

The gastrostomy is performed while you are under the general anaesthetic. Depending on what other operation you are having, a separate small cut may need to be made in your stomach. The tube is then passed directly into your stomach and may be held in place by some sutures. It will be covered by a dressing.

## After your gastrostomy insertion

After the procedure is finished a member of staff stays with you in the recovery area until the sedation has worn off, when you will be taken back to the ward. It is usually necessary to wait for four hours before you can use the tube and nursing staff will have been told exactly when feeding can be started.

## Will it hurt?

Whether you have a PEG or a RIG tube placed you will be given local anaesthetic. In most cases patients receive sedation too. Whether you receive sedation for your procedure or not will be discussed with you beforehand.

Once the sedation and local anaesthetic have worn off it is not uncommon to have some pain or discomfort around the tube site. Your doctor will have prescribed some painkillers for you which we recommend you take if you have pain. The discomfort can last for a few days, and you will be given painkillers to take home if necessary. If the pain is very severe, or does not go away, please tell a member of staff.

## **Risks and side-effects**

No treatment or procedure is totally risk free, but gastrostomy insertion is generally very safe. The main complications following gastrostomy are mentioned below:

#### Infection

Infection can occur after the insertion of the feeding tube. It usually occurs around the wound site. However, when antibiotic cover is given, the chances of infection are greatly reduced.

#### Chest infection or aspiration

Can occur after the procedure. This can result from lying flatter than usual for the procedure when you have swallowing difficulties already (if that is the case). You will then be given a course of antibiotics.

#### Bleeding

A small amount of oozing from the wound site is normal. However, sometimes the bleeding can be more noticeable. This will usually stop on its own accord but do inform the nursing staff. In a small number of cases (one per cent) you may need to be taken to theatre to stop the bleeding.

#### Perforation

Perforation of the bowel is a potential risk due to the nature of the procedure, but it very rarely occurs. It may not always be possible to diagnose this at the time of procedure but usually presents later as abdominal pain or bloating. This will be discussed further by your doctor or nutrition nurse before the procedure and at time of consent.

#### **Risks of sedation**

The main problem with sedation is that it can affect your breathing. For this reason, if you

have a chest infection, we may decide to postpone the gastrostomy placement until you have had a course of antibiotics and your chest infection has cleared. Your breathing is monitored throughout the procedure.

#### **Procedure failure**

In this case the tube is not placed because of technical difficulties. It is usually due to a person's individual anatomy, sometimes an undiagnosed hiatus hernia, or an unusually shaped stomach, that does not affect you in any other way but makes it impossible to place the tube. We will then reassess why it could not be placed and agree a plan B with you – usually one of the other 2 procedures.

#### Mortality

As with any surgical procedure there is a very small chance that you will not survive. Because of this we make sure that you are as fit as possible to undergo the procedure and we will choose the technique that will be safest for you.

#### How will I use the gastrostomy tube?

We will show you how to use the tube whilst you are in hospital and give you a booklet with more detailed information. Special liquid food, water and most medicines can be put down the tube using a large syringe. In some cases, it may be appropriate to use a blended diet of ordinary foods.

Your dietitian will discuss this with you if it would be appropriate for you. As well as using a syringe to administer the feed, you may be given the feed using a special pump which gives the feed slowly over a longer period, such as overnight. If you or your carer(s) are unable to set up the feed, for whatever reason, it is usually possible to make alternative arrangements. We will have discussed this possibility with you before the tube is placed.

#### How will I know I am looking after it properly?

Before you go home from the ward the dietitian and nurse will check that you (and/or your carer) know how to look after your gastrostomy. The training can be carried out by the nutrition nurse provided by the feed company.

The training usually happens before you are discharged but can be done at home if this suits your needs better. Either way, they will contact you after you go home. The community dietitian will also contact you when you get home. Sometimes a district nurse or trained carer is involved too. You will also have a 24hr help line telephone number.

#### What other support is available when I go home?

You will receive a discharge information pack before going home which includes details of a national support group for any patient who has had a gastrostomy.

Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT) is a national, independent, not for profit membership charity providing mutual support and understanding to hundreds of adults and children and their families adapting to life on home artificial nutrition. You can find them at <u>pinnt.com</u>

## How long will I need it?

The tube will be removed when you are eating and drinking enough, and you no longer need to use it to provide extra nutrition. In some cases, you may need the tube permanently, but your medical team will have discussed this with you. However, this does not prevent you deciding that you want the tube to be removed anyway.

## How is the gastrostomy removed?

This will depend on the design of tube you have. Most PEG tubes are removed in endoscopy. It will normally be removed in hospital this is very straight forward and takes only a few minutes. Most RIG tubes can be removed at home by deflating the balloon.

## Can I have a bath or shower?

You can shower from the day after the tube has been placed. Baths must be shallow - avoid soaking the site for at least two weeks, until it has healed.

## Can I go swimming?

Yes, once the site has fully healed. We usually recommend waiting four weeks but talk to your healthcare provider if you have concerns.

## Will I be able to wear normal clothes?

Yes. The tube can be covered with normal or loose clothing but will show under tight clothing. You may find it more comfortable to wear your waistband below your gastrostomy tube. There are also a few gastrostomy belts on the market which you can buy and your dietitian can help you find one that suits your needs.

## Do I have to pay for the feeds?

No, not if you are in NHS patient and are registered with a GP. Both the feed and the equipment are paid for and will be delivered to your home at a time that will be arranged to suit you.

## Do you have any further questions?

Feel free to use the space below to write down any other questions you may have and ask any member of the team. No question is ever too minor or too silly to ask, so do ask about anything that is unclear.

#### **Contact us**

We hope that this leaflet has answered some of the questions you have about having a gastrostomy. If you have any questions or require any further information, please do not hesitate to ask any of the staff or contact us below.

Royal Free Hospital: 020 7794 0500 Royal Free Hospital nutrition nurse: 020 7830 2612

## Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: <u>rf.communications@nhs.net</u>

## **Alternative formats**

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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