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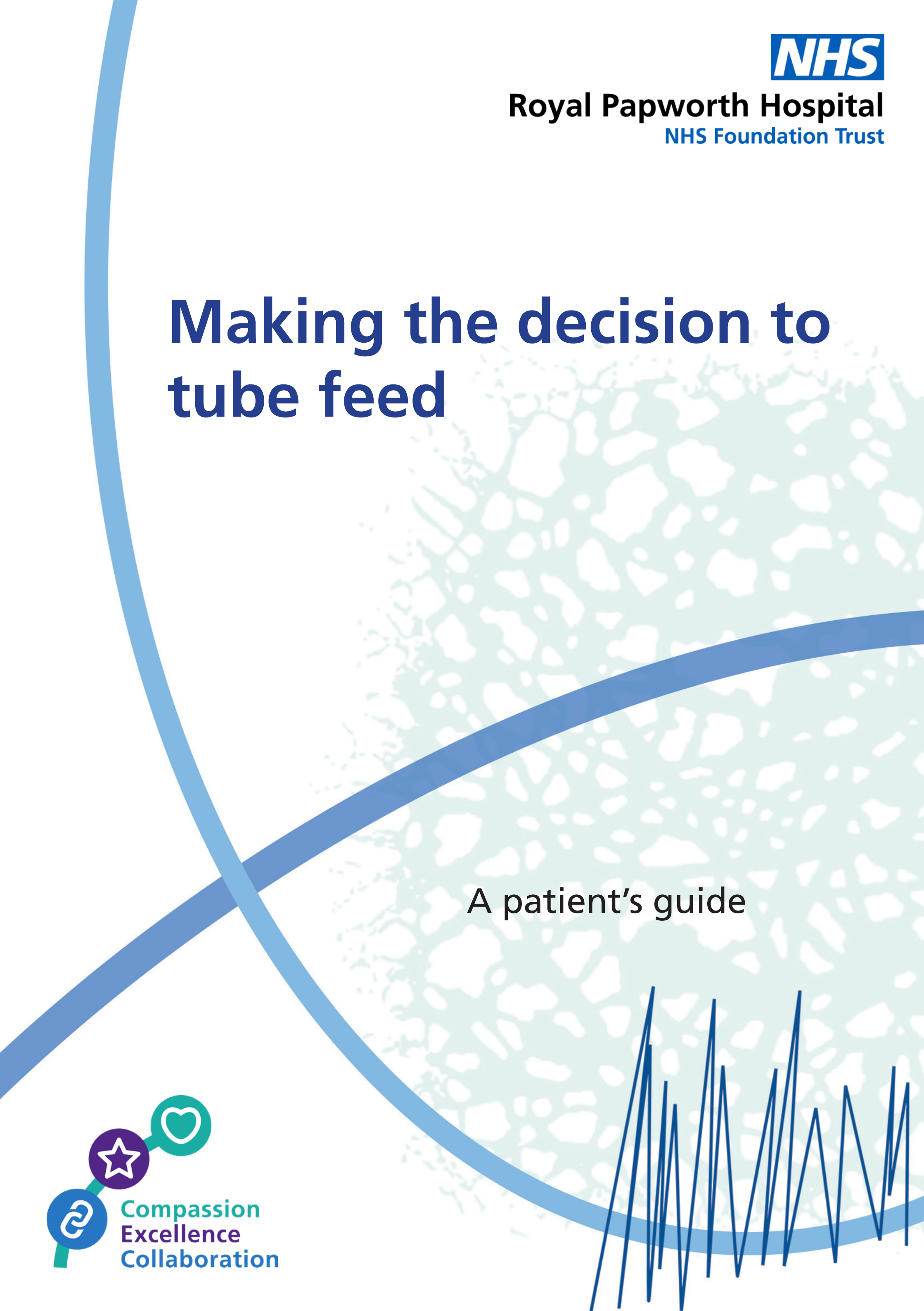
Making the decision to tube feed



A patient's guide

Compassion
Excellence
Collaboration

This booklet is designed to help you to think about whether tube feeding is right for you. It aims to support discussions with your dietitian, doctor or specialist nurse, not replace them.

You may have lots of questions, some of which may not be answered here. You can talk to your dietitian, doctor or specialist nurse as often as you need to.

What is tube feeding?

Tube feeding is sometimes referred to as enteral feeding. It is a way to provide you with nutrition to help you to meet your energy, protein and hydration needs. It comes in the form of a liquid feed that is given directly into your stomach via a tube.

You may not be able to obtain enough calories through eating, despite your best efforts. Or you may have a swallowing difficulty which means you are not able to eat safely. Tube feeding, therefore, can be as a 'top-up' or can provide all your nutrition.

The tube can be placed in different ways. These are discussed later in the booklet.

Why tube feed?

Tube feeding may help you:

- Maintain or gain weight
- Fight infections
- Keep hydrated
- Have an improved sense of well being
- Reduce the pressure to increase the amount you eat

It is important that you feel fully informed and involved in the decision. Often it takes people some time to think about tube feeding and whether it is right for them. It is therefore important that where possible we discuss tube feeding early so that you have time to consider your options.

We need to also ensure that you are well enough for any possible procedure that may take place. Some of the pros and cons of the various feeding methods are outlined in this booklet.

How do I use the tube to feed?

You will be recommended a specially prepared liquid tube feed by your dietitian. There are many different types available. The specific type used will depend on your unique situation. This can be given in two different ways.

Bolus method

The liquid feed is fed into the tube by a syringe over a relatively short period multiple times in a day.

Pump feeding method

The rate of the feed is controlled by a pump; usually this method is used for feeding over a few hours.

There can be a lot of flexibility with tube feeding. Your dietitian will focus on devising a feeding plan with you that fits your needs, lifestyle and preferences as far as is possible.

Specific types of tube feeding

There are several different types of feeding tube. All the methods discussed here enable you to feed directly into the stomach.

Nasogastric (NG) feeding

This is where a thin pliable tube is placed from your nose into your stomach. This is usually placed by a doctor or nurse. There are circumstances when some people may be trained to place tubes themselves, though this is not always possible.

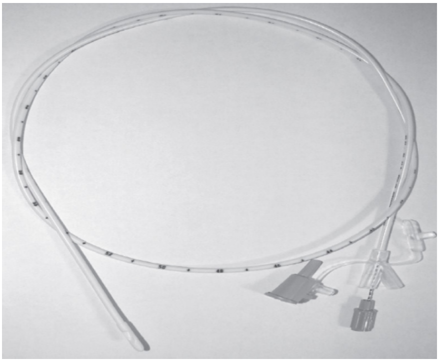


Image of NG feeding tube

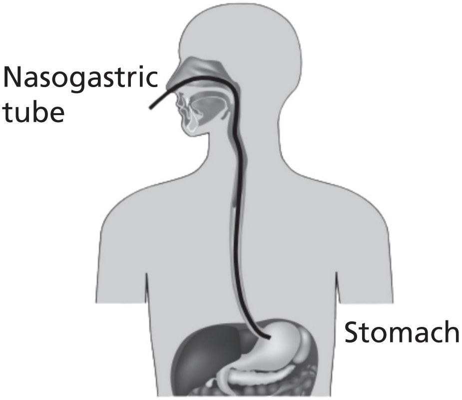


Image of how the feeding tube works

Pros

- It can be a temporary option if you need to tube feed only for a short period of time.
- You do not need a surgical procedure.
- NG tubes may be used at home, but only if you are trained to insert the tube safely yourself. This option is not suitable for everyone and should be discussed with your dietitian.

Cons

- The tube is visible whilst you are feeding.
- If you feel sick or are vomiting, you may find it difficult to insert the tube or keep it in.
- Some people find it more difficult to eat and drink with the tube in place, although most people get used to it quickly.
- The tube position must be checked before each time it is used to ensure it is in your stomach.

- There is a risk of the tube becoming displaced with coughing which may result in it having to be replaced regularly.

Gastrostomy feeding

Percutaneous endoscopic gastrostomy (PEG). The name is related to how the tube is placed:

P – Percutaneous, by way of the skin

E – Endoscopic, an endoscope is an instrument used to examine the stomach to aid placement of the tube

G – Gastrostomy, surgery making an opening into the stomach

A gastrostomy tube is inserted directly into the stomach during a surgical procedure. Usually, you will need to have the tube placed with an endoscope under sedation. Your doctor will discuss with you whether you are well enough for this. Endoscopy is a term used to describe examining the inside of the body using a lighted, flexible instrument called an endoscope. The whole process usually takes about 30 minutes, and you will be drowsy while it is happening.

An example of a PEG tube is shown below:

Taken with permission from Cambridge University Hospital NHS Trust gastrostomy booklet

Pros

- You will not have to have an NG tube on show all the time.
- It may be hidden under clothing.
- If you have not been able to tolerate an NG tube or need to tube feed every day this is a more suitable option.
- These tubes are held in place with a bumper or a disc and are unlikely to be dislodged.

- PEG tubes can last months or years before needing to be changed.

Cons

- Your tube will be visible on your stomach but usually can be hidden with clothing.
- When the tube needs to be replaced or removed you are likely to need to go back to endoscopy for this.

Balloon retained gastrostomy

This is a type of gastrostomy that is retained in the stomach by a small water-containing balloon. A PEXACT tube is an example of a balloon retained gastrostomy tube. It is usually placed with an endoscope.

Pros

- Replacing the tube does not require another endoscopy. The balloon is deflated allowing the tube to be removed and replaced.
- Tubes can be replaced by arrangement with community nurses or specific hospitals.

Cons

- The tube is often longer than a PEG so there will be more tube visible on the outside.
- Most tubes have a specific period, such as weeks or months before they need to be replaced.
- There is a chance that balloon retained tubes could become displaced more easily than a PEG with a bumper or disc. Displacement is unlikely if the water in the balloon is checked weekly. Checking the water is a simple process which usually can be done at home by yourself, a relative or carer.

Image of PEXACT tube

Low profile device or 'button'.

If you have had a PEG or balloon gastrostomy placed you may be able to have a 'button'. Although this is not suitable for everyone.

Pros

- This is a low-profile device which is closer to the skin and less visible than a PEG or balloon retained gastrostomy.
- This can be changed by an appropriate nurse or hospital or by yourself, a relative or carer after training.

Cons

- You may need to have a PEG or balloon retained gastrostomy first as this ensures that the tract (hole into the stomach) is well formed.
- Buttons should be changed at least every six months to ensure that the balloon remains effective.

An extension tube needs to be attached before using the tube.

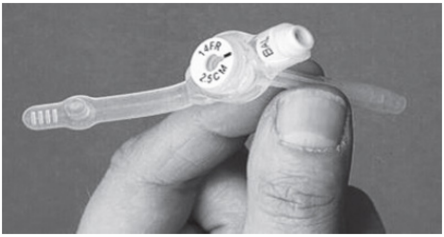


Image of PEG/balloon gastrostomy 'button'

What are the risks of a gastrostomy?

Before you go for a procedure your doctor will discuss the risks fully with you.

You will be assessed for your suitability for the procedure to reduce any potential risks. All concerns about the risks and benefits of a gastrostomy procedure should be discussed with your doctor.

How do I get the equipment I need?

If you feed whilst in hospital all the equipment will be provided for you. If you feed at home, your dietitian will register you with a home feed delivery company. You will then usually receive all your equipment at home. You will have to consider storage space.

All this will be discussed in more detail if you need to feed at home. You or an appointed carer will be trained on how to use your tube and any equipment you need.

There are several different types of feeding companies in the UK. You may not necessarily have the same feed and equipment at home as in hospital. If this is the case it will be discussed with you, however all the feeding systems are similar.

How long will I need the tube for?

This varies from person to person. You may need to have the tube only for a fairly short period of time such as weeks. Or it may be a longer-term option such as months, years or indefinitely. Your dietitian will discuss this with you.

How do I look after the tube?

Whatever type of tube you have, you will need to flush it with water whenever being used and at least daily. This is to ensure that it does not block. If you have a gastrostomy tube you will need to clean around the site daily to help prevent soreness and infection.

Infection is unlikely if the tube and site is looked after as advised. You or your appointed carer will be trained on the care of the specific tube you have.

Am I likely to encounter any problems?

You may get problems with tube blockage, infection, leakage or displacement. Some people may have issues with tolerating a sufficient volume of feed. You will be taught how to check that your tube is in the correct position if you are changing any tubes yourself.

These problems can all be minimised by following the instructions on care of your tube and by discussing any issues with your nutrition nurse or dietitian as soon as you notice them.

This booklet is designed to give you an introduction to some of the feeding methods and the types of feeding tube available.

Not all tubes are suitable for everyone, and all queries or concerns should be discussed with your doctor, dietitian or specialist nurse in conjunction with reading this booklet.

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