

Making the decision to tube feed

A patient's guide

This booklet is designed to help you to think about whether tube feeding is right for you and 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, sometimes referred to as enteral feeding, is a way to provide you with additional nutrition to help you to meet your energy requirements. This comes in the form of a liquid feed that is given directly into your stomach, or other part of your gastrointestinal tract, via a tube. The tube can be placed in different ways. These are discussed later in the booklet.

Why tube feed?

Tube feeding can help you gain weight, or maintain your weight, when you are unable to manage sufficient food or oral supplements. Tube feeding

will only help if you use the tube on a regular basis.

It is important that you feel fully informed and involved in the decision making process. 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.

What are the benefits for me? Some of the pros and cons of the various feeding methods are outlined in this booklet.

In general, people often have an improved sense of well-being as their nutrition improves and it can help your body fight infection. In conditions such as cystic fibrosis there is a strong link between body weight being in the normal range and improved survival.

Sometimes people are not able to meet their daily energy needs through eating, despite their best efforts. Some people may need to consider tube feeding if they have difficulty in taking enough energy orally due to problems with swallowing or if they are no longer able to safely have food or drink via mouth.

Tube feeding can help to close the energy gap which will result in better nutrition and contribute to better overall health.

General considerations
Many people who use tube
feeding to 'top-up' their
intake comment that it takes
the pressure off trying to eat
enough and can enable them
to start enjoying food again.

When you are trying to gain weight or when eating is difficult due to nausea or other problems, food can become a chore. If you have been told you are unable to safely eat or drink, your dietitian will discuss with you how tube feeding can used to provide all your nutritional and fluid needs.

How do I use the tube to obtain extra calories?

You will be recommended a specially prepared liquid tube feed by your dietitian. There are many different types available. The feed is usually given via an electric pump which provides a certain amount of feed every hour.

You can also 'bolus' feed where you give yourself liquid feed via a syringe. The feeding method that suits you best should be discussed with your dietitian.

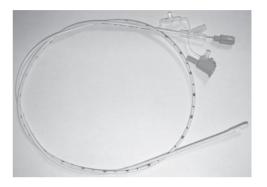
There is a lot of flexibility with feeding and your dietitian will devise a time, rate and amount that is suitable for your specific requirements and lifestyle as much as possible.

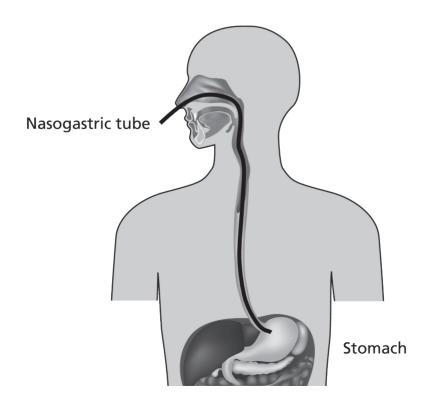
Specific types of tube feeding

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

Nasogastric feeding (NG)

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.





Pros

- It can be a temporary option if you need to tube feed only for a short period of time.
- The tube is not permanent.
- This tube can be used shortterm in hospital during a period of illness or to help you to gain weight.
- 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 can then allow feeding at home at night and the tube removed in the day. 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 and can eat and drink as normal.
- The tube position must be checked each time before 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 (PEG)

PEG (Percutaneous Endoscopic Gastrostomy). The name is related to how the tube is placed:

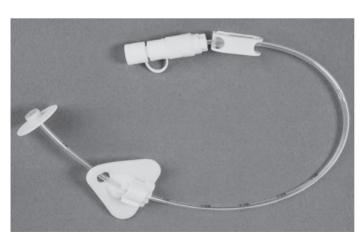
P - Percutaneous by way of the skin

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

An example of a PEG tube is shown below.

A gastrostomy tube is inserted directly into the stomach during a surgical procedure. There are several types of gastrostomy tube and one suitable for you will be chosen. 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.



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 feel sick you do not have to try to insert an NG tube before you can feed.
- 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

- This is a longer term feeding method. Your tube will be visible on your stomach but usually can be hidden with clothing.
- Generally the tubes last for months or years without needing to be replaced.
 However, you would need to go back to endoscopy to have the tube changed or removed.

Balloon retained gastrostomy

This is a type of gastrostomy that is retained in the stomach by a small water-containing balloon rather than by a bumper or disc as in a PEG. 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 significantly bigger than a PEG so there will be more tube visible on the outside
- Most tubes have a specific length of time, 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 or by a relative or carer.



Low profile device or 'button'

People who have had a PEG or balloon gastrostomy placed may be able to have a 'button' (shown below) although this is not always 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. This helps to reduce the risk of problems with the tube, such as infection.
- Buttons should be changed at least every six months to ensure that the balloon remains effective



What are the risks?

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 PEG 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 so that you will 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 and 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 (weeks) or it may be a longer term option (months, years or indefinitely). You will need to discuss this with your dietitian.

How do I look after the tube? Whatever type of tube you have, you will need to flush it with water daily 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. This will be discussed specifically with you, depending on which type of 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 by measuring pH (acidity) 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 dietitian.

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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