

An introduction to PEG feeding

Talking Points - Leaflet No: 3



This is an introduction to PEG feeding (short for percutaneous endoscopic gastrostomy) for people who have or are going to have a PEG tube inserted. Or for those who care for someone with a PEG tube, or who may be going to have one put in.

Why do I need a PEG?

A PEG is used in people of all ages, including children and babies, who are unable to swallow or eat enough and need long term artificial feeding. Your doctor or healthcare team might talk to you about the need for artificial nutrition (known as a form of tube feeding) because you have a condition which it makes it hard to swallow food and enough fluids.

Will I always need a PEG tube?

Some conditions affect people for a short time and other people need their tube feed for many years. Your doctor and healthcare team will be able to talk to you about this. The team usually consists of a doctor, dietitian and a nutrition nurse and may have input from a speech and language specialist.

How is a gastrostomy tube inserted?

When your doctor has discussed the need for the tube you will sign a consent form. The doctor will make sure you fully understand what is going to happen. Make sure you ask any questions before signing the form. It does not matter how simple you might think the question seems. The team caring for you will want to make sure you understand everything you want or need to know.

Most people hear different names for the gastrostomy tube. You might hear the name 'PEG tube' or 'G tube'. If you do not understand what is being said please ask.

You will usually be taken to the Endoscopy department to have the tube put in. Some people need to have general anaesthetic and others are given some sedation and medicines to keep them relaxed whilst the doctor puts the tube in.

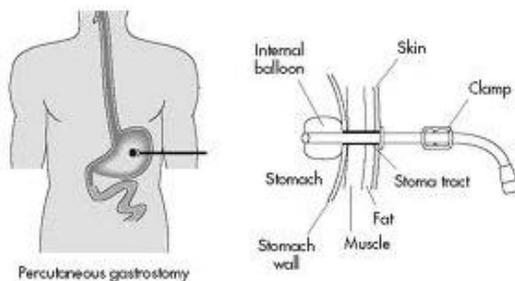
Usually it takes around 10 – 15 minutes and you will wake up in the recovery room where the nurses will look after you until you are awake enough to go back to the ward, or go home if you are well enough to have your tube put in as an outpatient.

Because you will have a small incision (cut) made for the tube to come out from the stomach to the skin you may feel a bit uncomfortable afterwards. Please tell your care team and they will be able to help you with this.

You will not be able to use the tube for at least a few hours if this is your first gastrostomy tube you have had. The nurse and dietitian will be able to advise you and support you as you have your first water and feed through the tube.

How do I care for my PEG SITE?

You will be shown how to keep your PEG site clean. To start with the site may feel sore and you might have some sticky fluid from the site where the hole they had to make is healing up. It can take up to a few weeks for some



people to find their PEG site has healed properly. Do not worry about this because you will be cared for or shown and told what to do.

Some people are at home and might need care from the community nurse or dietitian in the early days to make sure the site is clean and healing well.

Each hospital care team have different ideas and so please do not worry if you have read or heard about the need for sterile dressings and saline. Some hospitals do not use these and other patients might need them.

It is very important to keep everything clean and you will have been taught how to look after your tube and site by your care team either at home or in hospital. If you have forgotten or are worried please ask them again as it's not worth taking any chances or being worried.

Do I need special water for my tube?

Even if you are not using your tube for feed you will still be given instructions on how to flush the tube with water. In most cases tap water is used, although in some areas cooled boiled water or sterile water is needed especially for people who may have problems with their immune system and are at even more risk of infection.

Can I have a shower or bath?

If you are well enough ask when you can have a shower. It will probably be about a month before you can have a bath or go swimming but again check with your health care team.



My site looks red and sore.

If you have redness or pain or feel you have any other problem with your PEG tube or care of your site contact your nurse, doctor or dietitian who will be able to give you advice and support.

It is very important not to rush or skip any stage of your PEG site or PEG tube care. Take your time and you will soon become confident and used to what is normal for you and how to manage these things each day.

Will the liquid food be like ordinary food?

The food you will need will be a liquid in a sterile container. It does not look like ordinary food and is not always a very nice smell or colour either! Your dietitian will talk to you about the type of feed you need. Some people need a lot more of one type of feed than another patient and so do not worry if other people are managing their feed in a different way to you. The feed contains all the calories and other essential nourishment such as vitamins and minerals that you need. Some of this will depend on what is wrong with you, how heavy you are and how much fluid you need in a day.

How will I know what to do?



The dietitian will write a plan with you [or for] and you will be able to have a copy of this to check especially in the early days of managing at home alone. They will also tell you how much water to use before and after your feed or medication. It is very important that you do this so you get some water and also to stop your tube blocking.

If you think your tube is blocked please follow the advice you have been given or contact one of your medical team straight away by telephone for advice on what to use and who to see for help.

When will I be fed and how?

Each patient has different needs and so the dietitian will have worked out a plan for you. Some people have their feed when they are asleep and do not have any feed during the day.

Others have only day time feeds and carry their feed in a backpack or shoulder bag as they are up and about in the day time.

Bolus feeding can also be used which is using a syringe to slowly let the feed drip into the stomach through an enteral feeding syringe.

Some people use a mixture of both methods and vary the times of the feed according to their daily routine and care needs. Your dietitian will be able to talk to you about this.

Some patients might still be able to eat and drink normally and need their feed to give them extra calories and nutrients.

Will I need to use a lot of different equipment?

Your healthcare team will arrange for you to learn how to care for your PEG and new needs before and possibly shortly after having your PEG put in.

The equipment will seem strange and possibly you will feel awkward about using it to begin with.

Why are the syringes purple?

You will have special syringes which are purple (UK). These are designed to fit onto the end of your tube and can only be used for enteral [tube] feeding or medication and oral medications. This is a safety feature so that in hospitals they cannot be used for other types of care and treatment which other patients might need. Some syringes need a small plastic adapter on the end of the PEG tube so that they fit and others do not need this. Your care team will advise you and show you what to do.



If you have been advised that you can use a syringe for a few times or a day then please follow their advice about washing these and storage. It is very important that you keep things very clean and dry when not in use.

What is a feed pump?

If you will be using a feed pump so that a slow measured dose of feed can be pumped (infused) into your stomach you will need to learn how to set this running and what to do if the alarm sounds. Do not worry about the alarms as they are there to warn you that something needs your attention such as the bottle of feed being empty.

How will I obtain my supplies?

Many areas arrange for your supplies to be delivered to your home by a homecare company who look after the needs of patients all the time. You will probably have a named worker in the company who you can contact and order your supplies when you need them. Sometimes they arrange to call you and check that you have enough of all of your equipment and feed.

In other areas the community nurse might be responsible for delivering some or all of your equipment each month such as syringes and the hospital to homecare company just deliver your bottles of feed.

You will need a dry clean cupboard or other safe place to keep your supplies but you can have as much each time as you can cope with storing and so do not worry about this.

Your hospital to homecare company or nurse will also give you an emergency number to call in case you have problems with your pump outside of office hours.

Will I still feel hungry or thirsty?

People who use gastrostomy feeding are unlikely to feel hungry. You may feel thirsty and so if your doctor has said you can manage small sips of water this is a good idea.

If, like many people, you cannot drink it is even more important to have very good care of your mouth. If you have problems with a very dry mouth ask your doctor if there is some help with this as some products might be suitable on prescription to help you.



In very hot weather or if you are unwell with another condition or infection you might need some extra water like everybody else. Check with your health care team and if you need advice about how to fit it in with your usual feed regime your dietitian will advise you.

Tell your health care team if your mouth is sore and dry as they might need to give you some treatment for this or a spray to help keep your mouth moist.

Do I still need to go to the dentist?

It is very important that you still visit your dentist and that they know you cannot manage to eat or drink. We all need to care for our mouth and teeth and again the dentist may be able to offer some good advice and care if you have limited or no oral fluids.

Will I still be able to have a social life?

Yes you can! You might have already had to start to make adjustments if your condition has been a long term problem.

Having your PEG feeding might make you wary of going out and how you will cope with explaining things to those you meet.

The best way is to explain it in simple but clear words for example that your illness means you cannot eat and drink and so this is an ideal way of getting all you need to stay well nourished. Answering questions

might seem like the last thing you need but most people will be supportive and you are still the same person!

You can still go out if you are well enough and if you have to stay inside more often there are still plenty of ways of keeping in touch with your friends and family. You can even find new hobbies and interests or discover enjoyment in trying some of the things you have always wanted time to try and do!

Make sure you have plenty of time to rest and if you are finding you are getting too tired especially if you have been ill in hospital set limits to phone calls. Explain to people that you will be in touch again soon and will look forward to short and enjoyable chats or visits so that you can focus on feeling stronger. Again most people will understand this situation.

Can I go back to work?

This will depend on your illness and how you feel and should be discussed with your doctor.

If you're well enough and once you have settled into a routine and adjusted to your feeding, artificial nutrition need not stop you from working.

If you cannot work and this is a sudden change it will feel hard and upsetting to begin with. Do not be afraid to seek help with those feelings as they are normal and should not be ignored. Gradually you will come to find new ways of spending your time and enjoying life again. This might include a new hobby or interest. It might even be possible to try some voluntary work or even in time return to some paid employed employment. Keep in contact with your doctor and care team and if this is becoming difficult they can possibly suggest somebody to assist you with this situation.

Will I be able to go back to school?

Yes, your feeding will not stop you going to school. Your doctor and the team looking after you will talk to you about this especially if you have been very ill in hospital for a long time. The staff at school will be there to look after you will possibly need to be shown how to manage your feed and equipment if you cannot do this yourself. They will also need to know what to do if you are poorly and cannot manage things so easily.

Specially trained children's nurses work in most areas and will probably be the people who go to school and chat about these things. Sometimes they will do this with you and with your parents or whoever is looking after you most of the time.

It might seem like there are lots of rules but these are there to keep you safe. If it seems to be taking a long time to sort out getting all your equipment and feeds you might be able to manage some school work at home.

PINNT have a section for children called half PINNT. Why not get in touch and chat about how other children manage at school too? There are leaflets about managing at school available from the PINNT office.

Will I be able to travel?

We all need a break now and again. Being on artificial nutrition should not prevent you from travelling. You will have to be organized and careful planning will help especially if you want to go abroad. Try to give your hospital and your home care supplier as much notice as possible and they can assist you with all your necessary feed arrangements.

Before making any arrangements it might be a good idea to let your doctor and other health care team members know of your plans, especially if you are having ongoing care and treatments.

PINNT are delighted to dedicate this booklet to Mr Geoff Simmonett. Geoff was a Trustee of PINNT, served as Treasurer and chaired LITRE. Geoff had a very positive outlook on life and never let his PEG hold him back. He faced life on enteral feeding with great determination and lived a full and happy life. Geoff was keen to support fellow enteral patients and one of his last projects for PINNT was to produce this resource.

Please note: whilst every care has been taken by PINNT to ensure that the content of this booklet is accurate, no liability in respect of such content or any omission is or will be accepted by PINNT.

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