

Talking Points 3

PINNT

PO Box 3126
Christchurch
Dorset BH23 2XS

Website: www.pinnt.com

Email: info@pinnt.com



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Talking Points 3

An Introduction to PEG Feeding



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An Introduction to PEG Feeding:

CONTENTS

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 may be going to have one put in.

Why do I need a PEG ?.....	4
How do I care for my PEG site ?.....	5
Can I have a shower or bath ?	6
When will I be fed and how?.....	7
What is a feed pump ?.....	8
Will I be able to have a social life ?.....	9
Can I go back to work ?	10
Will I be able to travel ?	11
Contact details	12



STEP-BY-STEP From your social life to hospital visits and home feeding, this pamphlet will help get you started with PEG feeding.

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PINNT
A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

Why do I need PEG?

You may have questions about why a PEG is needed, what will it mean to your daily life? And how you are going to manage?

Why do I need a PEG?

A PEG (Percutaneous Endoscopic Gastrostomy) 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 tube feeding (a type of artificial nutrition) because you have a condition which makes it hard to swallow food safely and/or fluids and medication.

Will I always need a PEG tube?

Depending on your condition you may need to use a PEG tube for a short time or 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?

Once you and your doctor have agreed you need a PEG, you will be asked to 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.

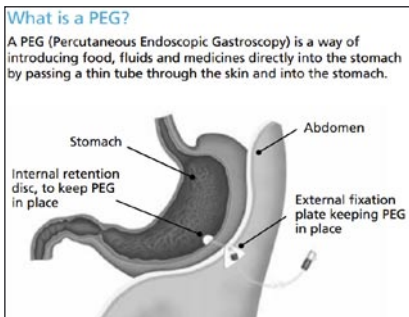
Most people will have their PEG tube inserted in the Endoscopy department. Most people are given a sedative to help them relax, but occasionally a general anaesthetic is needed.

How long does the procedure take?

Usually it takes around 10 – 15 minutes and you will wake up in the recovery area where the nurses will look after you until you are awake enough to go back to the ward, or go home.

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 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 advise and support you on when you can begin using the tube. Normally water is used first to check the tube is securely in the stomach, before any feed is administered.



How do I care for my PEG site?

It may take a few weeks for your PEG site to settle down, and you might need a little help/advice from your community nurse or dietitian on how to manage your PEG site and feed at home.

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 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. Your own hospital care team will provide you with guidelines on what to use to clean the site and whether dressings are needed. The advice may change after the first few weeks, once the site has healed.

Overall advice would be to wash your hand before accessing the PEG site or any open parts of the tube and to keep everything clean. If you have forgotten or are worried about anything, check with your nurse for advice. It is a good idea to ensure you have some written guidelines on how to contact your team if you need help when you are at home.

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.



DINNER TIME feed, pump and tube primed and ready

Can I have a shower or bath?

Using a PEG brings many changes to your daily routine, with lots to learn in the first days, weeks and months. Here are some more tips about bathing, maintaining PEG tubes and more.

Can I have a shower or bath?

You will be able to have a shower, bath and even go swimming once your PEG site has sufficiently healed. Your healthcare team will instruct you on their policy around when this can be done.

My site looks red and sore.

If you have redness, discharge, 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.



MEDICAL ADVICE If in doubt...ask lots of questions.

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. Everyone is individual in their needs, 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 nutrients, such as vitamins and minerals that you need. Some of this will depend on your condition, what you weigh and how much fluid you need in a day.

How will I know what to do?

The dietitian will write a plan with you (for you) 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 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?

Not everyone feeds using their PEG at night. You can feed during the day (example in action below) or a mixture of day time and night time feeding. Do what you feel comfortable with!

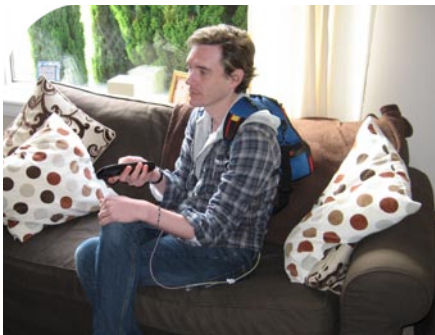
When will I be fed and how?

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 during 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 may be able to eat and drink but need their feed to give them extra calories, nutrients, fluids and medications.

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 feeding



LEISURELY LUNCH Mobile feeding at home.



BUSY AT WORK Feeding backpack in action.

needs, 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 can use a syringe which is 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.

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

What is a Feeding Pump?

Don't panic when you hear the feeding pump alarm for the first time. It's probably an empty bottle that needs filling.

What is a feed pump?

If you will be using a feeding pump so that a controlled 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 you have enough of all of your equipment and feed on a regular basis.

In other areas the community nurse might be responsible for delivering some or all of your equipment each month such as syringes, whilst your 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 homecare company or nurse will also give you an emergency number to call in case you have problems with our pump outside of office hours.



CONTROL Pumps like this regulate your feeding.

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.

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

Will I still have a social life?

Obviously things will be different, so talk to your friends - you will be surprised at how supportive everyone is. Also, why not make some new contacts through PINNT and share some hints and tips.

Do I still need to go to the dentist?

It is very important that you still visit your dentist and that they know you have difficulties eating and drinking. 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 family and friends. 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 when you first come home from hospital, then 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.



LET'S CHAT You are the same person and your friends will be more supportive than you could ever imagine.

Can I go back to work/school?

Simple answer: wait until you have settled into the new way of feeding and then see how your routine unfolds. How about a new hobby or interest and maybe some voluntary work?

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 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.



MAKE IT WORK You can carry on with your life.

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 and 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 may 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 has 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 - contact us via www.pinnt.com

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 organised and careful planning will help especially if you want to go abroad.

Try to give your hospital and your homecare 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 healthcare team members know of your plans, especially if you are having ongoing care and treatments.

PINNT is 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. The information in this guide is intended as general information only and is not intended to be relied upon by any individual in relation to their specific circumstances. It is not intended as a replacement for appropriate professional advice.