

# TUBE FEEDING

## Information for people affected by Progressive Supranuclear Palsy (PSP)

This information sheet will help you to explore the options available to you so that you can make an informed decision about alternative methods of eating and drinking.

When you have Progressive Supranuclear Palsy (PSP) you may find that you develop swallowing problems, making eating and drinking effortful and tiring. You may find that you are not able to eat and drink as much as you did before, resulting in weight loss, a lack of energy and feelings of frustration. You may experience problems with swallowing that cause you to cough whilst eating and drinking. This occurs when the mechanism of swallowing is affected, as it is easier to aspirate food which means that food can accidentally slide into the lungs, rather than into the stomach which can lead to chest infections.

If you are experiencing these problems, your speech and language therapist and dietitian can assess you to help you decide on the best course of action (if you do not have a speech and language therapist or dietitian, your GP can make a referral on your behalf). This may include alterations to your diet, such as changing the consistency of your food and fluids to make them easier to swallow.

However, as PSP progresses you may find that swallowing problems become more severe. If this happens then you may wish to consider alternative methods of eating and drinking.

## What are alternative methods of eating and drinking?

An alternative method of feeding is one which avoids taking food by mouth. There are two main options of alternative feeding:

**Nasogastric (NG) feeding** – this involves putting a tube through the nostril, passing it down the back of the throat and in to the stomach. Liquid feed and water can be passed through this tube, avoiding the need to swallow. NG feeding can only be used as a short term measure, and therefore may not be suitable for people with long term conditions such as PSP.

**Feeding via a Percutaneous Endoscopic Gastrostomy (PEG) tube** – this involves inserting a small tube directly through the abdomen into the stomach, ie Percutaneous (through the skin) Endoscopic (it is placed using an endoscope) Gastrostomy (feeding tube). Ready mixed liquid feed and water can then be passed through the tube directly into the stomach, avoiding the need to swallow. This is more comfortable and easier to manage than a nasogastric tube and is therefore more suitable for people who require alternative feeding methods on a long term basis. It should be noted that you can choose to continue to eat and drink by mouth for pleasure, as well as using a PEG tube for feeding.

## Will I need to stay in hospital?

Having a PEG tube fitted does involve a short stay in hospital, but usually only overnight. However, this may vary depending on local NHS policy. In most cases the procedure is performed under a light 'conscious' sedation to help you feel relaxed, rather than a general anaesthetic, and takes approximately 30-60 minutes.

## What are the risks of having a PEG fitted?

All surgical procedures carry a risk however, PEG placement is a relatively safe procedure. There are risks of infection, skin irritation, bleeding from the wound, abdominal pain, and bowel perforation associated with the procedure, (although bowel perforation is a rare complication). It is important to note that you may experience some abdominal soreness or discomfort for a number of weeks following the procedure. This is often eased by simple pain medications and should lessen after the first few days as healing takes place. Once completely healed, no pain or discomfort should be experienced. After a short time you will be able to bath or shower as normal.

## What are the benefits of having a PEG fitted?

The major benefit of PEG is that it enables you to obtain adequate food and drink, which may improve your quality of life in a number of ways. Dehydration and malnutrition can be quickly addressed, and this can help to improve general health and provide a sense of wellbeing and increased energy levels. If you have lost some weight then you may find that having the PEG helps you to regain a few extra pounds and then keep the weight on. If you are having problems with constipation then you may find that PEG helps you to take more water, or take specially formulated feeds, which can help to improve this. If you have to take a lot of medications, these can be given through the tube and so save you having to take them by mouth.

The risk of chest infections is lower because the risk of aspirating food into the lungs is reduced (although it is important to note that you can still aspirate if you have problems with excessive saliva. If this is the case please contact your GP who can discuss options to help reduce this symptom). Furthermore, PEG can relieve the anxiety and stress that is often felt at mealtimes if swallowing is an issue. Having a PEG will reduce the amount of time you need to spend trying to eat, allowing you extra time to spend on something more enjoyable.

However, it is important to note that whilst PEG feeding provides important benefits it will not halt the progression of PSP, or change the course of the disease. If you have issues with thick saliva you may find that increased fluid intake can help this.

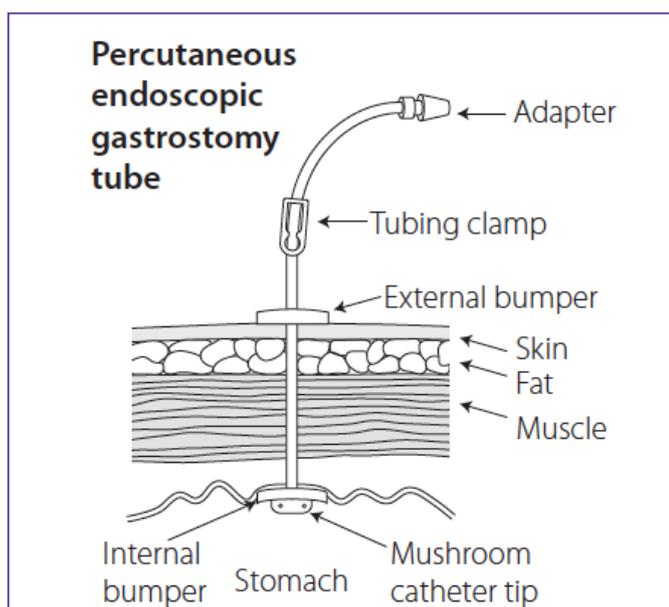
### When should I have PEG fitted?

Whilst PEG can be considered at any time, many people find that they gain the most benefit from it during the early and middle stages of PSP. In these stages it is easier to take a planned, controlled approach. Whilst it is possible to have PEG fitted in the later stages of PSP, it is important to note that the benefits may be limited. Also, in the later stages of the illness, the procedure may prove more difficult if you are having problems with your breathing due to chest infections, and you find lying flat difficult.

It can be hard to think about having a procedure like PEG when you are still managing to eat and drink, but it is important to have an understanding of what is involved so that you can make an informed decision about your future care. Remember, a PEG can be placed and not used until it is needed (with only daily flushing and cleaning of the tube required to maintain it). Furthermore, if you are still managing to safely eat and drink small amounts, then PEG can be used to help you top up your calorie intake.

### What is the PEG tube like and how do I care for it?

The PEG is a flexible tube that is roughly the size of a drinking straw. It is held in place internally using a small disc or 'bumper' which prevents it from falling out. There is also an external



bumper for added security, which is worn close to the skin. This can easily be moved up and down the tube to allow for cleansing of the area. There is a small adaptor at the end of the tube through which the feed is administered, and there is a small clamp on the tube which is used to halt the flow in the tube when the end is open.

The dietitian or specialist nurse will visit you before you are discharged from hospital to show you how to clean and take care of the tube and surrounding skin. They will also teach you and your carers how to administer change to feed, water and medications using the PEG.

There are two main ways of being fed using the PEG tube and your dietitian will help you to decide which method is the best to fit in with your lifestyle.

**Bolus feeding** – liquid feed is fed into the tube using a needlessly syringe, mimicking a meal pattern. Up to five feeds per day is typical.

**Pump feeding** – liquid feed is dripped into the tube over several hours via an electric pump. It may be possible for this to take place overnight to fit in with your lifestyle.

One or both of these methods of feeding can be used, depending on your preference. The tube can last anywhere from eighteen months up to five years before needing to be replaced, although some last even longer than this. Replacing the tube involves a minor procedure, usually without the need for a hospital stay.

It is still possible to bathe, shower and swim when you have a PEG tube, although it is usually best to wait until the PEG tube exit site is fully healed. The dietitian or specialist nurse will provide you with specific guidance on this.

They will also advise you on what to do, or who to contact should any problems arise when you get home, such as tube blockages, sore skin around the exit site or what to do in the unlikely event that the tube falls out.

## **Choice of liquid feed**

The liquid feed is designed to provide you with all of the nutrients that you require on a daily basis. The exact content will vary depending on your individual needs. For example, you may require a feed with extra calories if you have lost weight, or you may require a feed with extra fibre if you are having problems with constipation. Your dietitian will decide the best type of feed for you, and will also take into account any allergies that you may have. The feed is prescribed for you and can be delivered straight to your home.

## **Will I still be able to eat and drink by mouth?**

Having a PEG tube does not necessarily mean that you have to stop enjoying food and drinks by mouth. Whilst you may need to have the majority of your nutrition via the PEG, it may still be possible to take or taste food and fluids by mouth. However, it is important to seek advice from your dietitian and speech and language therapist to ensure that eating and drinking is safe for you, as well as advising you on the most suitable type, consistency and amount of food for you.

## Oral hygiene

Please be aware that it is still important to continue with good oral hygiene and teeth brushing. Plaque can build up very quickly so it's important to clean your teeth at least twice a day whether or not you continue to eat, as poor oral hygiene can lead to chest infections.

## Can I put medications down the PEG tube?

It is possible to administer some liquid/soluble/dispersible medications via the PEG tube. Please seek advice from your doctor, district nurse or pharmacist about medications that are suitable for PEG tube administration. Please remember that it is important not to put anything down the PEG tube other than feed, water or medications.

## Thinking ahead – is PEG feeding right for me?

It is important to remember, as with any medical intervention, that the decision to have a PEG tube fitted is yours alone. Take time to talk through all of your concerns to make sure that you have all the information that you need to make an informed decision. Even after these conversations have taken place, you can still decide not to have a PEG placed – talking about it does not mean you have to have it done.

You may be concerned that having the PEG would prolong your life past a point where you feel you have quality of life. Alternatively you may be concerned about how you will manage in the later stages if you decide not to have a PEG fitted. You should be given time to discuss all of your concerns with the relevant health professionals.

If you decide not to have PEG fitted then you will still need to be supported by the health professionals to continue with eating and drinking as long as possible, and to help alleviate any symptoms associated with being less able to eat and drink.

It is important to make your wishes known as early as possible. Whatever decision you make, please remember that you can change your mind at any time. However, as PSP progresses it can affect both speech and cognition, which can make it difficult to communicate your wishes. If you are no longer able to make decisions for yourself you are said to have lost 'mental capacity'.

## Planning ahead – Advance Care Planning and Advance Decision to Refuse Treatment

If you decide that you do not want to have PEG fitted either now or in the future, you may find it helpful to make people around you aware of your decision.

It can feel overwhelming to talk about issues that may affect you as you reach the later stages of PSP. Some people prefer not to talk about it at all as it may bring to mind issues about PSP, and about the future that they are not yet ready to think about. Others prepare as soon as possible, giving everyone a chance to talk and share their feelings. It can give you piece of mind to be prepared emotionally and practically. Planning your future with the people in your life may help you, your family and friends to feel more confident and reassured with what lies

ahead. This process is known as advance care planning (ACP). As part of your plan you may wish to explore your thoughts, feelings and preferences on a number of issues, including Advance Decisions to Refuse Treatment (ADRT).

An ADRT is a choice you can make in advance to refuse specific life sustaining treatments in the future, to ensure that your wishes are adhered to. It is a legally binding document which only becomes valid if you lose the ability to communicate your decisions (often referred to as losing mental capacity). You may wish to complete an ADRT to reflect your choices if you decide that you do not want PEG. This will ensure that your wishes are adhered to should you lose the ability to make decisions in the future.

If you lose mental capacity and do not have an ADRT in place, then your healthcare team will make decisions on your behalf in the event that you require any treatments. They will do this with your best interests at the heart of their decision. Please be aware that whilst they will take on board any thoughts that your next of kin may have regarding what you may have wished for in the circumstances, they may override them if they feel that this is the best clinical option.

For more information on ACP and ADRT, please speak with your GP. You may also wish to contact the PSPA's Helpline and Information Service.

## **PEG in the final stages of life**

As we approach the end of our lives, our bodies naturally require less food. This is no different for people who have PEG. To ensure your comfort your dietitian (and palliative care team – if they are involved in your care) may suggest changes to the amount of feed that you receive via PEG during the later stages.

## Useful contacts

PSPA Helpline and Information Service

Tel: 0300 0110 122

helpline@pspassociation.org.uk

[www.pspassociation.org.uk](http://www.pspassociation.org.uk)

PINNT – a support group for people receiving artificial nutrition

PO Box 3126, Christchurch, Dorset BH23 2XS

Tel: 020 3004 6193

[www.pinnt.com](http://www.pinnt.com)

## Further information

We provide other sheets related to this information:

*Advance Decision guidance notes for people living with PSP and CBD.*

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