MSA Trust

Factsheet

Tube Feeding

This factsheet has been developed to help people with MSA understand why tube feeding may be something to consider as a supplement or alternative to taking food by mouth. It describes the process of having a PEG tube fitted and explains the risks. A PEG tube is the most common way of inserting a feeding tube.

What is a PEG tube?

A PEG tube is a thin tube that comes into the stomach through a small hole made in the abdomen. This allows liquid feeds, fluids and medications to go directly into your stomach without the need for you to swallow it.

PEG stands for:

Percutaneous - formed through the skin

Endoscopic - placement of the tube

Gastrostomy - surgical formation of an opening through the abdominal wall into the stomach

When to start thinking about a PEG

Your Doctor, Speech and Language Therapist or Nurse Specialist (this could be an MSA, Parkinson’s or Neurology Nurse) may discuss with you the possibility of having a PEG if they recognise that you are showing some early signs of changes with your swallow.

It is good to start considering this early so you have time to think about what is involved in having a PEG inserted, whether this is something you would want and time to ask any questions you may have about it.

It is best to think about a PEG before considerable weight loss has occurred and before you are at risk of chest infection due to aspiration (inhalation) of food into the airway. Before making a decision, you may want to discuss it with your family and other professionals such as, your Speech and Language Therapist and Doctor.

Can anyone have a PEG?

There may be some people with MSA for whom a PEG is not an option due to other health considerations or because they are too frail and unwell generally for the procedure to be done safely. The medical team assessing you for a PEG will only undertake the procedure if they feel it will be of benefit to you and not cause greater harm.

For most people with MSA having a PEG fitted is something that can be planned for and you can choose whether you think this is a good option for you.

Sometimes a PEG is fitted when someone is already in hospital having been particularly unwell and so is done as a more urgent procedure to assist their recovery. Wherever possible it is best to have a chance to think about whether you would want a PEG feeding tube. There is no right or wrong answer. What is important is getting a chance to ask any questions that you may have a and the information you need to make the decision that is right for you.

Continuing to eat and drink

Many people with MSA continue to take some foods and/or drinks by mouth after a PEG has been fitted. You may even enjoy them more because you can eat just small amounts and only the foods you like, without having to worry about getting enough to eat. Your Speech and Language Therapist will advise you about what is safe for you and what types of food and drink are suitable.

The benefits of PEG feeding

Difficulty in swallowing can become distressing for all concerned. PEG feeding can remove this anxiety, which often accompanies meals and allows you to get all the nutrition you need from a specially prepared liquid feed.

Sometimes the effort and the time it takes to eat a full meal reduces the pleasure we normally get from eating and drinking. A PEG can be used to ‘top-up’ your nutrition if after 20 minutes or so you have had enough of eating. It is also a good way to increase your fluid intake, especially if you need to take extra fluid to maintain a good blood pressure, or maintain good urinary flow through a urinary catheter. Being able to increase your fluid intake generally will also help reduce fatigue, reduce constipation, keep your airway secretions loose and reduce urine infections.

PEG feeding may reduce the risk of chest infections, which can result from small amounts of food and/or fluid entering the airway during swallowing. However, the muscle at the top of the stomach may be less efficient in people with MSA so food can back up into the food pipe and still go down the airway. To reduce this risk it is suggested you sit as upright as possible whilst eating and during a PEG feed. Remain sitting up for 1 to2 hours if possible after a PEG feed. Also, chest infections can occur from saliva going down the airway, these will not be prevented by having a PEG.

For most people with MSA having PEG feeding provides an improved sense of wellbeing as your energy levels increase. If you have lost a lot of weight your dietitian may prescribe a high calorie feed to help you regain some of it. After this, the type and amount of feed will be adjusted to help keep your weight at the right level for you.

Many people with MSA have trouble with their bowels. The reasons for this include weakened pelvic floor muscles and poor fibre and/or fluid intake associated with swallowing difficulties. It can take a while for the bowels to get back to a normal pattern and your Dietitian may advise the use of a special feed with extra fibre if constipation is a problem.

A PEG can be used to have your medications too. Not all medications can be put down a PEG tube but most can and the pharmacist can advise you on the appropriate preparations of the medications you take. This can be particularly helpful when acutely unwell as at these times swallowing can be more difficult than usual and you may have extra medication to take.

What a PEG does not do

A PEG does not stop the progression of MSA or stop all risks of aspiration pneumonia. As already mentioned, saliva and reflux of stomach contents can still be aspirated into the lungs causing pneumonia.

How is the PEG tube put in?

You will need a short stay in hospital, often overnight, sometimes for a couple of days.

- A general anaesthetic is not usually required and you will not be unconscious, but it is unlikely that you will remember much about the procedure. You will be given an injection beforehand that will provide pain relief and make you relaxed and sleepy.
- A qualified Nurse will remain with you throughout the procedure.
- In order for the Doctor to see where they need to insert the PEG tube, they will pass a tube (an endoscope) into your mouth and down into your stomach. This will not interfere with your breathing and will not be painful but it may be uncomfortable. A small amount of air is put into the stomach to obtain a good view.
- The PEG tube is then positioned in the stomach. A small hole is made in the skin, in the upper part of the abdomen, for the tube to pass through.
- On the inside of the stomach a small disc on the end of the tube prevents it from falling out. A small clip holds the tube securely on the skin surface of the abdomen.
- If the PEG tube is held in place by a disc inside the stomach this tube will not need to be routinely replaced. If the tube becomes damaged or needs replacing this will be done in hospital by the team who insert the tubes.
- If the tube is held inside the stomach by a balloon filled with water (the water is changed weekly through a valve on the side of the tube), this tube is usually changed every 12 weeks by a Nurse who specialises in tube care. They will visit you at home to do this.

What are the risks?

- A sore throat after the endoscope part of the procedure is common but should resolve after a few hours
- There is a small risk of damage to crowned teeth or dental bridgework

- There is a small risk of an infection occurring during the procedure, most commonly when the tube comes out onto the abdominal skin surface. An antibiotic will be given to reduce the risk and treat any infection
- There is a small risk of bleeding where the tube passes through into the stomach
- There is a very small risk of significant problems with PEG insertion, the team doing the PEG procedure will discuss this with you.

What happens next?

Whilst in hospital you will be shown how to look after the tube, how to clean the area around the tube and how to use the tube for food, fluids and taking medication.

What can I put down the tube?

Through the tube you can take:

- Your food - There are many types of specially formulated liquid feeds that can go down the PEG and your Dietician will determine which is the best for your needs. The Dietician will arrange for the feeds and supplies to be prescribed by your GP and delivered directly to you
- Medication in liquid form
- Water
- It may be possible for other fluids to be taken but this must be discussed with your Dietitian first as some liquids can corrode the tube.

You can choose to use the PEG as much as you wish, and you can still eat and drink what you can safely manage and enjoy. We strongly recommend that you follow the advice of your Speech and Language Therapist regarding this.

People often feel much better after the PEG tube is in place. Mealtimes can be less of a struggle and it can assist effective nourishment and hydration. Weight loss may become less of an issue. You should feel less tired, hungry and thirsty than before the PEG was inserted.

Initially, you will be given water through the PEG and the dietitian will work out an individual regime for you to ensure you have the correct calorific intake and nutritional balance.

Recuperation

The stomach and abdomen will heal in five to seven days. Any discomfort can be treated with medication.

You, your carer or family will be taught:

- How to care for the skin around the tube
- Signs and symptoms of infection
- What to do if the tube is pulled out
- Signs and symptoms of tube blockage
- What feeds to use and how often
- How to hide the tube under clothing

- When normal activities can be resumed.

What else do I need to know?

You will be able to take a shower soon after the PEG is inserted and after two weeks you can take a bath and go swimming

You can go out and will find the PEG tube can be easily tucked away under clothing

It is wise to ensure the tube is curled up and securely fastened to your abdomen to reduce the risk of it being caught and pulled when getting dressed or moving about.

What happens if I decide not to have a feeding tube?

Overtime with MSA eating and drinking becomes more difficult for most people, so without a tube you will lose weight and be less well hydrated. As this happens, gradually your body adjusts, and you become less thirsty and hungry.

The Speech and Language Therapist and Dietician will help you and advise about food.

The Trust’s contact details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – https://www.msatrust.org.uk/support-for-you/hcps/.

T: 0333 323 4591 | **E**: support@msatrust.org.uk | **W**: www.msatrust.org.uk

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References for this information sheet are available by contacting support@msatrust.org.uk.

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