
MOTOR NEURONE DISEASE

FACT SHEET No 10

Gastrostomy

Not everyone with Motor Neurone Disease will develop problems with swallowing, but for some it will become an increasing problem, and alternative ways of meeting nutritional needs may need to be considered.

A percutaneous endoscopic gastrostomy (PEG) may be helpful for some people if swallowing has deteriorated to such an extent that eating has become difficult, dangerous or insufficient. The option of having a feeding tube should be discussed as soon as problems with feeding become apparent, as receiving a feeding tube early in the disease, provides a better outcome (Mitsumoto and Munsat, 2001).

A PEG is inserted in hospital, usually by a gastroenterologist, and requires only a short stay - usually only a day or two. You are given an injection to make you feel sleepy, but not a general anaesthetic.

The doctor then passes an endoscope (a special, fine fibre optic cable telescope) into your mouth and down into your stomach.

The light at the end of the fibre optic cable can be seen from the outside to reveal its exact location. A small area of skin on your abdomen is injected with local anaesthetic and a little cut made in the skin.

A needle is then pushed into the stomach and a wire passed through and pulled up to your mouth as the endoscope is pulled upwards.

A tube is then passed over this wire and then the wire and tube are pulled back

down into your stomach and out of the small cut in the abdominal wall.

The tube is then fixed in place using a special plastic fixator (flange) and a stitch may be made to ensure that the tube does not become loose.

The whole operation only takes 15 to 30 minutes and you are fully alert a few hours later. The insertion of a PEG should not be painful, although you may feel some discomfort when the endoscope is passed down into the stomach.

Once a PEG has been inserted, it will be tested, by putting some water down the tube. Feeding via the tube can start the day after the tube is inserted and a dietitian will be able to advise on the feeds that can be used.

The tube need not interfere with food intake by mouth (if still safe), but can supplement regular oral intake. Some people will need to receive all their nutrition and medications via the tube. If total nutrition is needed there are 3 options:

- the tube can be connected to a pump that slowly pushes the liquid food through the tube and into the stomach
- feeds can be given in bolus form several times a day
- gravity (drip) feeds, where the tube is connected to a bag containing liquid food and the flow is regulated like an intravenous drip

It is important to discuss the different feeding methods with a dietitian before the operation.

Once the cut has completely healed, you can have a bath and even swim, as long as the tube is closed off. When the tube is not being used for feeding, it can be kept taped to the stomach and is hardly noticeable. Sometimes the tube can be replaced with a "button" once healed, which sits flush with the abdominal wall.

The decision about whether or not to have a PEG inserted can be a very difficult one. The fact that you need to consider using an artificial method of feeding can be hard to accept, and there are often fears that having a tube there will restrict what you can do.

However, a PEG will allow you to be properly nourished without the problems that may have been experienced, such as long and distressing meals.

Some people may not even use their PEG at first, keeping it in reserve in case feeding becomes more troublesome.

If your breathing tests begin to show that your breathing muscles are becoming weaker, then it is important to consider if you would like a PEG inserted. There is an increased risk of complications if the procedure is delayed.

Anyone who is having difficulty maintaining nutrition or who is having frequent episodes of choking should consider having a PEG inserted.

It is important to discuss the whole issue with your carers, nurses, doctors, dietitian or other professionals and it may be helpful to discuss the pros and cons of a

PEG with others, particularly with someone who has a PEG themselves.

FURTHER SUGGESTIONS REGARDING PEG

Make sure that you speak to a dietitian before having a PEG to discuss the method, quantity and cost of feeding.

Some hospitals are able to supply formula (enteral) feeds at cost for people who are for PEG. Some pharmacies provide a small reduction in cost.

Daily care of PEG Site

The normal PEG tube site is flat, dry and not tender. Fresh air and a daily shower or bath is all that should be needed for its care.

Immediately following discharge from hospital, it is advisable to arrange regular follow-up from a community nurse who is experienced in PEG care.

There is a flange attached to the PEG tube site where it enters the stomach. This will need to be gradually released in the days immediately following the operation. If this is not done irritation of the skin surrounding the stoma may occur.

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Acknowledgements:

*Motor Neurone Disease. A family affair, David
Oliver*

Sheldon Press, 1995

*Amyotrophic Lateral Sclerosis. A Guide
for Patients and Families.*

H. Mitsumoto and T. Munsat,

Second Edition, Demos Medical Publishing, 2001

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