

Considering gastrostomy – PEG and RIG

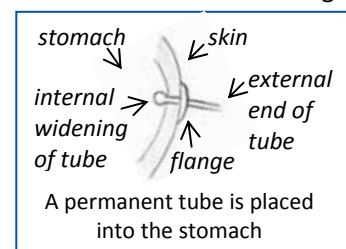
What you should know

- MND causes the muscles you have control over to weaken. This can include the muscles involved in chewing and swallowing.
- Gastrostomy is a medical procedure during which a short, permanent tube is placed into the stomach through the abdominal wall. You can have liquid feeds and fluids through the tube, directly into your stomach, bypassing your mouth and throat.
- Research shows that people with MND who have a gastrostomy may live longer and have an improved sense of well-being.
- In Australia, two common methods are used to place the permanent feeding tube: percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG).
- People sometimes delay making the decision to have a gastrostomy. However, it is important to know that other symptoms of MND, such as respiratory muscle weaknesses and malnutrition, can affect your recovery from the procedure or prevent you from having a gastrostomy.

About gastrostomy

Gastrostomy is a medical procedure during which a short, permanent tube is placed into the stomach through the abdominal wall. This procedure involves an injection of a local anaesthetic, a small incision and, depending on the type of gastrostomy performed, mild sedation.

Once the permanent tube has been positioned into the stomach it is prevented from moving by a widening of the tube internally and a small flange or collar externally. A cap is placed over the external end of the permanent tube. You can tuck the external end of the tube under your clothes when it is not in use.



Fluids and liquid feed can be provided through the external opening of the tube. This type of feeding is called enteral feeding. It is commonly suggested for people who have complex medical conditions or disabilities affecting their ability to swallow.

The permanent tube generally lasts for one to two years and can usually be replaced easily. Changing the tube does not usually require hospital admission.

Gastrostomy and MND

Motor neurone disease causes the muscles you have control over to weaken. This can include the muscles involved in chewing and swallowing.

When a person has weakness in the muscles involved in chewing and swallowing they may eat and drink less than they usually would, cough during mealtimes, take a long time to eat or be worried and anxious about eating and drinking. This can result in weight loss, malnutrition, dehydration and a loss of enjoyment of life.

Gastrostomy enables you to have enteral feeds and fluids through a small permanent tube that passes directly into your stomach, bypassing your mouth and throat. If you have lost weight or have become dehydrated through inadequate nutrition, enteral feeding may increase or maintain your weight, improve hydration and help to reduce tiredness and hunger. Some people with motor neurone disease can continue to take some foods and fluids by mouth after a gastrostomy.

Research shows that people with motor neurone disease who have a gastrostomy to get adequate nutrition may live longer and have an improved sense of well-being (Langmore 2006, Anderson 2007). Your motor neurone disease will, however, continue to progress with or without a gastrostomy.

Types of gastrostomy

In Australia, two common methods are used to place the permanent feeding tube. Both usually involve mild sedation and a hospital stay of several days. Talk to your doctor about the right sort of gastrostomy for you.

Percutaneous Endoscopic Gastrostomy (PEG)

PEG takes about 30 minutes to complete.

1. An endoscope, a flexible instrument used to examine the inside of the stomach, is passed via the mouth into the stomach and, after the area has been anaesthetised, a small incision is made through the abdominal wall.
2. A guidewire is inserted into the incision from the outside
3. The guidewire is brought up through the endoscope into the stomach with the feeding tube attached.

Radiologically Inserted Gastrostomy (RIG)

RIG takes about 60 minutes to complete.

1. A fine, soft tube is inserted via the nose into the stomach. A liquid which shows up on an X-ray is passed down the tube into the stomach.
2. A local anaesthetic is injected into the abdominal skin and a small incision is made. The feeding tube is then inserted through the incision using X-ray guidance.
3. Several stitches are used to close the incision.

Points to think about

Hospital

Sometimes, people with motor neurone disease who have a gastrostomy need specialised respiratory management during the procedure. Having your gastrostomy at a hospital that is very familiar with the particular health needs of people with motor neurone disease may reduce your risk of complications (Forbes 2004).

Complications

Complications of gastrostomy for people with motor neurone disease have included tube displacement, tube obstruction, infection, gastrostomy failure and, less commonly, gastric haemorrhage and death during, or in the weeks following, the procedure (Langmore 2006). Researchers are still evaluating the best ways to reduce the risk of these complications. Areas of research interest include the effect of respiratory muscle weakness and whether the gastrostomy is performed at a hospital where health professionals are very familiar with the particular health needs of people with MND.

Getting advice about gastrostomy

To get advice about gastrostomy, talk with your general practitioner, neurologist, speech pathologist, dietitian, MND clinic, service or association.

References

- Andersen et al, 2007, 'Good practice in the management of amyotrophic lateral sclerosis: clinical guidelines. An evidence-based review with good practice points. EALSC Working Group.', *Amyotroph Lateral Scler* 8(4), 195-213.
- Forbes RB, Colville S, Swingler RJ and SMNDR Group 2004, 'Frequency, timing and outcome of gastrostomy tubes for amyotrophic lateral sclerosis/motor neurone disease—a record linkage study from the Scottish Motor Neurone Disease Register.', *J Neurol* 251(7), 813-817.
- Langmore SE, Kasarskis EJ, Manca ML, Olney RK. 2006, 'Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease', *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.CD004030.

Respiratory muscle weakness

If you have a very weak exhalation caused by respiratory muscle weakness you may be more at risk of complications during and after the gastrostomy procedure (Anderson 2007). Therefore if you think you might consider enteral feeding as an option in the future, you may need to have the gastrostomy before you really need one for nutritional reasons, but while your respiratory function is above a certain level.

Lifestyle

When making the decision, some thought needs to be given to the changes needed once the tube is in place, for example, hygiene, skin care and using the tube for fluids and feeds when away from home.

Changing your mind

As MND progresses, you may change your views on enteral feeding. You may want to have a gastrostomy or, if you have had a gastrostomy, you may decide to discontinue using enteral feeding.

Living Better for Longer: MND Australia evidence-based fact sheets

- MND evidence-based interventions - an overview (EB1)
- Breathing and motor neurone disease: an introduction (EB2)
- Breathing and motor neurone disease: what you can do (EB3)
- Breathing and motor neurone disease: medications and non-invasive ventilation (EB4)
- Multidisciplinary care (EB5)
- Multidisciplinary care team (EB6)
- Riluzole (EB7)
- **Considering gastrostomy - PEG and RIG (EB8)**

© MND Australia 2009

MND Australia is indebted to the MND Association UK for permission to adapt their Information Sheet PEG feeding: making the decision.

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit www.mndaust.asn.au

EB8/200909