

## Considering gastrostomy – PEG and RIG

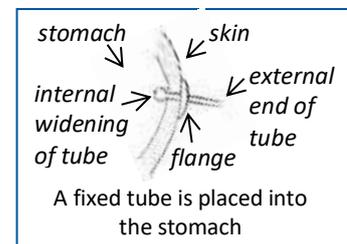
### What you should know

- Motor neurone disease (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, fixed tube is placed into the stomach through the abdominal wall. You can have liquid feeds, fluids and medications passed through the tube, directly into your stomach, bypassing your mouth and throat. The tube is the size of a small, narrow straw.
- Best evidence to date suggests that people with MND who have a gastrostomy may live longer and have improved nutrition.
- In Australia, two common methods are used to place the fixed 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, so the decision should not be left too late.

### About gastrostomy

Gastrostomy is a medical procedure during which a short, fixed tube is placed into the stomach through the abdominal wall<sup>1</sup>. This procedure involves an injection of a local anaesthetic, a small incision and, depending on the type of gastrostomy performed, mild sedation.

Once the 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 fixed 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 passed 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 fixed 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, become slow or uncoordinated<sup>2</sup>. 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 normal, cough during mealtimes, take a long time to eat or be worried and anxious about eating and drinking. Difficulty eating and drinking can result in weight loss, malnutrition, dehydration, aspiration pneumonia and a loss of enjoyment of life.

Gastrostomy enables you to have enteral feeds, fluids and medication through a small fixed tube that is fitted 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.

Best evidence to date suggests that people with motor neurone disease who have a gastrostomy to achieve adequate nutrition may live longer<sup>3,4</sup>. 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 fixed feeding tube<sup>5</sup>. Both usually involve mild sedation and a hospital stay of several days. Talk to your doctor about the right type 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<sup>6,7</sup>.

### 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<sup>8</sup>. Researchers have noted that there is a need to better understand the impact of gastrostomy, including its complications, and how it affects quality of life<sup>9</sup>.

### 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<sup>10</sup>. Therefore if you think you might consider enteral feeding as an option in the future, you may need to have the gastrostomy performed early 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 required once the tube is in place. Changes include hygiene, skin care and using the tube for fluids, feeds and medication 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.

## Getting advice about gastrostomy

To get advice about gastrostomy, talk with your general practitioner, neurologist, speech pathologist, dietitian, MND clinic or service or your MND Association. The online MND decision tool can also help you learn more about your options: [https://mnddecisiontools.com/public/1/decision\\_tool](https://mnddecisiontools.com/public/1/decision_tool)

References: 1. Agency for Clinical Innovation, 2014, *A Clinician's Guide: Caring for people with gastrostomy tubes and devices - Key Principles and Practice Points*. Retrieved from [https://www.aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0016/251062/Gastrostomy\\_Guide\\_Key\\_Principles.pdf](https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0016/251062/Gastrostomy_Guide_Key_Principles.pdf) 2. Schlüter et al, 2018, Risk factors for social withdrawal in amyotrophic lateral sclerosis/motor neurone disease, *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 19:7-8, 591-598. 3. National Institute for Health and Care Excellence (NICE) 2016, Motor neurone disease: assessment and management. Retrieved from <https://www.nice.org.uk/guidance/NG42/chapter/Recommendations#managing-symptoms>. 4. Ng et al, 2017, 'Symptomatic treatments for amyotrophic lateral sclerosis/motor neuron disease', *Cochrane Database of Systematic Reviews* 2017, Issue 1. 5. Lau et al, 2018, 'Multidisciplinary management of motor neurone disease', *Australian Journal of General Practice*, 47(9), 593-597. 6. Zhang et al, 2012, 'Nutritional support teams increase percutaneous endoscopic gastrostomy uptake in motor neuron disease', *World Journal of Gastroenterology*, 18(44):6461-7. 7. Kak et al, 2017, 'Gastrostomy tube placement is safe in advanced amyotrophic lateral sclerosis', *Neurological Research*, 39(1):16-22. 8. Katzberg, H. D. and Benatar, M. 2011, 'Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease.', *Cochrane Database of Systematic Reviews* Rev 1, CD004030 9. EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis, 2012, 'EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force', *European Journal of Neurology*, 19(3):360-75. 10. Gorrie, et al., 2019, 'Improved survival and 30-day mortality after gastrostomy in Scottish motor neurone disease patients: evidence from a national retrospective cohort study using STROBE criteria', *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 20(3-4):165-171.

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