Motor Neurone Disease NZ

Tube feeding/Gastrostomy with MND

Information sheet for people living with MND and their whānau

If the muscles involved in chewing and swallowing become weaker, you may:

- eat and drink less than you usually would
- cough during mealtimes
- take a long time to eat
- be worried about eating and drinking.

This can result in malnutrition – not getting enough nutrients into your body, weight loss, or dehydration – not enough fluid in your body and will have a negative impact on your wellbeing.

Your health team may suggest that you consider a gastrostomy and will discuss it with you. It is your choice whether you accept this or not.

Gastrostomy is a surgical procedure which takes place in hospital with a specialist known as a gastroenterologist. You will have a light anaesthetic or sedation before the procedure begins. A short, permanent tube is placed into your stomach through the abdominal wall. Liquid foods and fluids can then enter the stomach through this tube, bypassing the mouth and throat. Liquid medication can also be taken via the tube.

Tube feeding, also known as enteral feeding, may help to increase or maintain your weight, improve hydration and help to reduce hunger and tiredness.

Once this tube is in place it doesn't mean that eating and drinking through your mouth must stop immediately. It is still possible to enjoy some food and drink by mouth, while the tube helps to maintain adequate nutrition and hydration.

The correct timing of this procedure is important. If the decision is delayed for too long, your breathing may have deteriorated to the point that prevents you from having a gastrostomy.

After the procedure the gastroenterology clinical nurse specialist and dietician will guide you and your primary caregiver in the use and care of the tube. Complete liquid foods such as Fortisip are provided for you by the dietitian and fed into the tube.

Tube feeding can take place manually several times a day – known as BOLUS feeding – or a small electronic pump can deliver a steady flow of formula via the feeding tube. Continuous feeding often takes place at night.

A feeding tube is often referred to as a PEG or RIG – these names simply refer to how the tube was inserted, but the way it works is just the same.

PEG: Percutaneous Endoscopic Gastrostomy

RIG: Radiologically Inserted Gastrostomy

Please note: A gastrostomy is not suitable for everyone who has motor neurone disease. This will only be offered to you if it will be helpful in your case.

The MyTube website has informative short videos about feeding tubes for people with MND: mytube.mymnd.org.uk/

Motor Neurone Disease New Zealand is a charitable trust dedicated to making time count for people affected by MND by offering personal support; advocacy; education; and supporting research. Find out more at www.mnd.org.nz or call 0800 444474.

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