

Introduction

As MND progresses your ability to swallow may deteriorate causing you to choke while eating or drinking.

Chewing and swallowing food is a complex process involving many different muscles of the tongue, mouth and throat which are controlled by nerves that originate in the lower part of the brain. This area of the brain is often referred to as the “bulbar region” and since symptoms affecting speech and swallowing are associated with damage to this area these symptoms are often referred to as “Bulbar Symptoms.”

The Epiglottis

One of the important muscles involved in swallowing is known as the epiglottis. The epiglottis is no more than a flap of muscular tissue sited where the throat separates into the wind-pipe and gullet. The epiglottis’s job is to cover the gullet for most of the time, but to flip over and cover the wind-pipe to prevent food or drink going down the wrong way while swallowing is taking place. When bulbar symptoms start the damage caused by the disease can affect the nerves controlling the epiglottis and stop it from fully covering the wind-pipe during swallowing as it used to do. Should food or liquid enter the wind-pipe coughing and choking usually take place to clear the unwelcome materials. This is a natural response intended to keep foreign materials out of the lungs.

Just as with the other muscles the

abilities of the epiglottis are gradually eroded over a period of time as the disease progresses. Frequently the first difficulties are encountered when drinking liquids. Liquid does not hold together into a “bolus” in the way that many foods do when being swallowed and tends to run down the walls of the throat and can spill easily over the epiglottis into the wind-pipe.

Aspiration

If food or liquid enters the lungs it is described as having been “aspirated” and can trigger episodes of pneumonia known as “aspiration pneumonia.”

To give liquids extra “body” and help them hold together while being swallowed food thickeners, obtainable from pharmacies, are made by a number of different companies and can be mixed with favourite drinks. In general these thickeners are almost tasteless and their thickening effect causes the drink to hold together better as it is swallowed. In a similar way if foods become difficult to chew and swallow without choking they can be pureed with appropriate liquids such as stock, milk, gravy and so on and then thickened back up to the consistency of custard for easier swallowing. The appropriate use of food thickeners can delay the need for tube feeding for some time.

When, despite food and drink thickening, the ability to swallow becomes so poor that aspiration pneumonia is a very real possibility; then is the time to switch to tube feeding to maintain adequate

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

nutrition.

Nasogastric (NG) feeding

Nasogastric feeding is usually recommended only if you are likely to need to be given nutritional support for a short time. Unfortunately, due to the progressive nature of MND, a move to tube feeding is unlikely to be temporary; therefore a more permanent arrangement called a gastrostomy tube is used.

Gastrostomy Tube

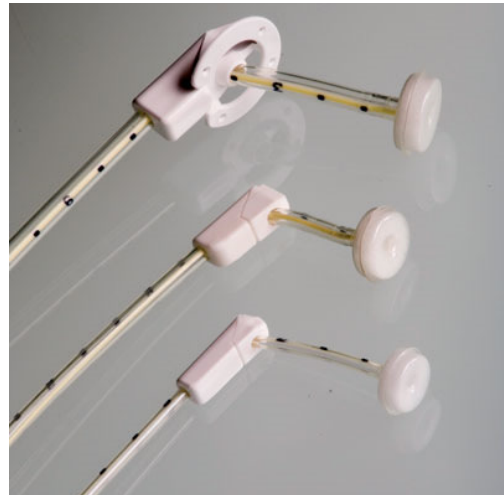
The possibility of fitting a gastrostomy tube might be raised long before the operation becomes a necessity. It is normal to monitor someone's breathing abilities when they have MND since experience has shown that once someone's breath-size drops to about half of normal they will have difficulty in recovering from the combined effects of sedation and lying on their back for the period of any surgery.



Once fitted there is no immediate need to use a gastrostomy tube if you still enjoy your food, swallowing is still possible and the risks of aspiration are acceptable. It will, however, be necessary to clean the wound and the tube daily to maintain

hygiene in accordance with instructions you will be given.

Your speech and language therapist will monitor and assess your swallowing and advise you when you should stop eating and drinking in the normal way. If you are unsure please check with your speech and language therapist or doctor.



Gastrostomy Tubes come in a variety of thicknesses.

Benefits of a Gastrostomy

A gastrostomy allows you to benefit from getting the nutrients you require. If eating and drinking has been a struggle or if mealtimes are taking up more time than you would like then feeding through a tube will free you to do the things you would like to do. You may find that you manage to eat more than before, and get more enjoyment from family mealtimes.

Feeding via a gastrostomy gives you the balanced diet you need to feel better, have more energy and resist infection.

There are three main ways in which feeding is carried out through a gastrostomy tube:

- By bolus method - the liquid feed is fed into the tube by syringe

- By gravity - a bag of liquid food is hung from a stand and allowed to drip through the tube
- By an electric pump which pumps the liquid food.

Your dietician will advise on the most suitable method for you and will recommend a specially prepared liquid feed which contains all the protein, energy, vitamins and minerals you need in a day. You may also require extra fluids via your tube. This special feed is provided by prescription and will be delivered. The dietician will also give advice on the amount of feed required and at what time of the day or night it should be given. *As a general rule, nothing your dietician has not approved should be passed through the tube as it may either damage or block it.*

Frequency of feeding

The length of time and frequency of the feeds is variable depending on individual requirements. The feeding may be continuous for 12–18 hours per day or by syringe (bolus) several times per day for 30-40 minutes. However, this can be changed to fit into your lifestyle – please discuss this with your dietician. Many people choose to feed overnight to minimise disruption to their daytime activities. It is vitally important to remember and maintain sufficient liquid intake every day, check with your MND Care Team Specialist, dietician or occupational therapist for advice.

The gastrostomy tubes themselves have a finite lifetime, but will usually last for up to a year. Removing and replacing a gastrostomy tube is a relatively simple procedure once the wound is healed. Discuss this with your MND Care Team Specialist if it is of concern.

Making the decision

The decision to have a gastrostomy is entirely yours. You may prefer not to be fed by tube but to continue the way you are, discussing any problems with the dietician and speech and language therapist. To help you make the decision ask questions of the professional staff who help with your care, taking every chance to gather information that will clarify things for you.

This is also an opportunity to talk about feeding in the later stages of the disease as well as discussing dietary problems affecting you now. When you have made up your mind, you may find that the decision you make is not the one that relatives and carers would like. Talking together will hopefully bring you to a shared understanding. As your MND progresses you may change your views on feeding. You may then wish to have a tube inserted or, if you have had one, you may decide to discontinue using it. Again, discuss this with your carers and family. *It is important to remember that your views and wishes will be respected.*

MND is a progressive illness and you may be well nourished at present. You may have been offered a gastrostomy to keep you in this good condition and prevent you from becoming malnourished in the future. Secondly, you may have been offered a gastrostomy because of increasing breathing difficulties that could eventually create problems bad enough to prevent surgery later. Alternatively your doctor may be concerned that your current dietary intake is not satisfactory and that if it is not improved via a gastrostomy you may develop malnutrition.

To insert a stomach feeding tube, commonly referred to as a **percutaneous**

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| When to Consider a Tube... | When NOT to Consider a Tube... |
|--|---|
| <p>When your weight goes 10% to 15% below your weight at diagnosis</p> <p>When eating or drinking leads to frequent choking and risk of aspiration pneumonia is increasing</p> <p>When it takes more than one hour to eat a meal</p> <p>When eating is no longer a pleasurable activity</p> <p>When respiratory function is decreasing</p> | <p>When your breathing function is considered too poor (see <i>Adapting to Changes in Breathing and Maintaining Lung Function</i> sub-section)</p> <p>When the idea of an incision or tube in the abdomen is unacceptable</p> <p>When the risks outweigh the benefits</p> |

endoscopic gastrostomy (PEG) tube, requires a simple 30-minute operation under mild sedation. A gastroenterologist will perform the operation. The tube is placed directly into your stomach through the abdominal wall to provide another way for you to receive nourishment and liquids.

Making your decision about a feeding tube

Making the decision to have a feeding tube is a major care decision when you have MND. Some people choose to have a feeding tube, while others do not. Each decision should be made based on available, accurate information and personal preferences. Whatever you decide, you should consider documenting your choice in your personal health care directive (See fact sheet 24 Powers of Attorney). Share a copy of your directive with your doctor, and discuss your decision with your family members, and in particular any individual who you might have appointed to be your proxy (legal representative of your wishes) in the event you cannot communicate your

wishes to healthcare providers. Use the above table to review issues to consider when making a feeding tube decision.

Keeping your Mouth Clean

Despite having a gastrostomy you will need to keep your mouth and teeth clean. Continue to brush your teeth as usual. A mouthwash or an artificial saliva spray may be of benefit to some people. A lip balm will help to keep your lips moist.

How Gastrostomy tubes are Inserted

Two common methods are used to insert gastrostomy tubes. Despite their differing names the end results are exactly the same; it is only the method of insertion that differs.

“**PEG**” stands for Percutaneous Endoscopic Gastrostomy. Percutaneous simply means the tube passes through the skin, “endoscopic” is because an endoscope is used to see the insertion point within the stomach and gastrostomy is a combination of two words “gastro” meaning stomach and “stoma” meaning mouth. Literally a “Stomach Mouth”

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“**RIG**” stands for Radiologically Inserted Gastrostomy since X-ray (Radiological) imaging techniques are used to visualise the insertion point rather than an endoscope.

Inserting a Percutaneous Endoscopic Gastrostomy (PEG)

The procedure requires a minor operation and is usually inserted under a local anaesthetic or a light general anaesthetic at your local General Hospital.

- An endoscope, a flexible instrument used to examine inside the stomach, is passed down into the stomach and, after the area has been anaesthetised, a small incision is made
- A guide wire is inserted into the incision from the outside
- The guide wire is brought up through the endoscope to be returned to the stomach with the feeding tube attached
- The wire is used to guide the end of the tube through the incision, leaving a retaining balloon inside the stomach to stop the tube from falling out
- The tube is prevented from moving back in by a small plastic disc placed over it on the outside
- A cap is placed over the end of the tube when feeding is not taking place.
- The whole process takes about 30 minutes to complete and you will be drowsy or asleep whilst it is

happening.

- If there is any discomfort after the operation you will be given medication to help.

Radiologically Inserted Gastrostomy (RIG)

- A fine, soft nasogastric tube will be put down the nose into the stomach
- A liquid which shows up on an X-ray may be fed down the tube into the stomach, this will allow the doctor to see the large bowel which must be avoided during the procedure
- On the day of the procedure, air will be put into stomach using the naso-gastric tube - the air moves the stomach into the right position
- A local anaesthetic is injected into the skin and a small incision made.
- The gastrostomy tube is then inserted directly into the stomach, under X-ray guidance
- Up to four stitches (called T-fasteners) are used and are removed after 10 to 14 days
- The naso-gastric tube is removed
- The gastrostomy tube is held in place by the same methods used in the PEG technique; a balloon on the inside and a small disc on the tube on the outside
- The process takes about an hour with only minimal discomfort from the nasogastric tube, gastric distension with air and skin sutures.

Neither procedure is without risks, although the RIG process has the advantage that it is done without deep sedation or general anaesthetic and can therefore be undertaken at a later stage than the PEG procedure. Unfortunately, there are very few surgeons in Scotland practiced in the RIG procedure; therefore it should not be assumed that a PEG can be refused with the possibility of a RIG later if you change your mind.

Post-operative adjustment period

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After the operation, you may have to stay in the hospital so that healthcare professionals can assess your body's ability to adjust to an alternate way of getting nutrition. How long a patient stays is dependent on his or her health. In some regions, the procedure may be performed as day-patient surgery followed by immediate home care support. A dietician will prescribe the quantity and type of nutritional supplements you should receive through tube feedings. During this period, you and your carer should learn how your new tube-feeding system works and how to manage your tube feeds. Even if you won't be using tube feeding right away, you will still need to practise flushing the tube twice per day to keep it clean.

Excessive coughing may occur

You may find that tube feeding causes excessive coughing. This may happen for a number of reasons, including excess saliva, not sitting up enough, the feeding rate is too fast, or because of various other stomach problems. If this happens to you, consult your dietician who may suggest reducing your feeding rate and/or decrease the amount of formula given at the feeding.

Avoid lying flat during and after feeding

If feeding overnight you need to remain propped up during the feeding and for another 45 minutes after the feed is completed.

Avoiding dehydration

It is a serious mistake to assume that you are getting enough liquid because you are living on liquid nutrients. Concentrated liquid nutrients do not

contain much water. Take lots of water to avoid dehydration. Your dietician will include in your tube feeding schedule how much water you need.

Tube-feeding diet

A dietician at the hospital will usually work out your tube-feeding requirements based on what you can still eat normally and your estimated calorie requirements. Because your eating abilities will change, your tube-feeding requirements will probably increase over time. Follow-up and any recalculation of your food requirements may be provided by a home care or community dietician.

It is important that your doctor and dietician become educated about MND. Encourage them to contact SMNDA for referrals to our MND Care Team Specialists with whom they can consult. Depending on where you live, products available may vary. Your dietician will recommend what is best for you.

Practical Care of Gastrostomies and Tubes

- Remember to always wash your hands before dealing with any aspect of your tube or carrying out the daily **inspection of** the site around the tube. Inform your district nurse or GP or MND Care Team Specialist if you experience any pain, redness, swelling or leakage around the site.
- The site should be cleaned daily with mild soap and water. Dry thoroughly. No dressing is usually necessary.
- Flush the tube with water before and after feeding or the administration of medicines.
- During feeding you should be

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sitting in a chair or propped up in bed with pillows. Do not lie flat during or for 45 minutes after feeding.

- No baths for two weeks after insertion – shower only.
- If the tube becomes blocked, flush with 50 ml of warm water or soda water.
- If your tube has a balloon to keep it in place the volume should be checked weekly. To prevent a build up of gas in the stomach, your district nurse will top up the volume and check the tension, if required.
- If the tube falls out or is accidentally pulled out a replacement tube needs to be inserted immediately. Contact your GP district nurse or NHS24 (telephone 08454 242424) in the first instance.

Some Frequently Asked Questions

How will I know how to use the tube?

You and your carer will be taught all about your tube and how to set up the feed while you are in hospital.

How do I get my equipment and supplies?

If the need for supplementary feeding is immediate the dietician will arrange the supply of feed and if necessary a pump and stand while you are in hospital having the gastrostomy. You will then need to obtain repeat prescriptions for your feed from your GP on a regular basis. The feed is delivered on a monthly basis.

How do I take my Medications?

Never try to push whole tablets down a feeding tube. You should ask your GP if liquid formulations are available to replace any tablets you take and always try to use medicines in liquid form. However, if you have to use tablets it is important to check with your GP or pharmacist that it is safe to crush the tablets and dissolve them in water. Some medications and tablets cannot be crushed as they are designed to be slow release. Crushing them might lead to an inadvertent overdose since almost all of the active drug would be available immediately rather than released over a period of hours. You should always let your pharmacist know that you are on tube feeding when he or she is supplying a new prescription.

It is very important to flush the tube with 50 mls of water before and after feeding and/or the administration of medicines. Discuss this with your Care Team Specialist or dietician.

Further Information

NHS24 is the national helpline for medical enquiries. Telephone number **08454 242424**

Factsheets

Factsheet 34 Adapting to Swallowing Problems
Factsheet 36 Oral Health

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