

Introduction to MND Education Day

Dietetics

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Motor Neurone Disease

- Motor Neurone Disease (MND) is a progressive neurodegenerative disorder that affects the motor neurons impacting muscles responsible for movement, speech and swallowing.

NICE Guideline NG42 – Managing Symptoms

- Nutrition and Gastrostomy
- At diagnosis and regular MDT, assess weight, nutritional intake, ability to eat and drink and consider gastrostomy early
- In addition use ALSFRS is a tool measuring progression of disability in people with ALS (otherwise known as MND)

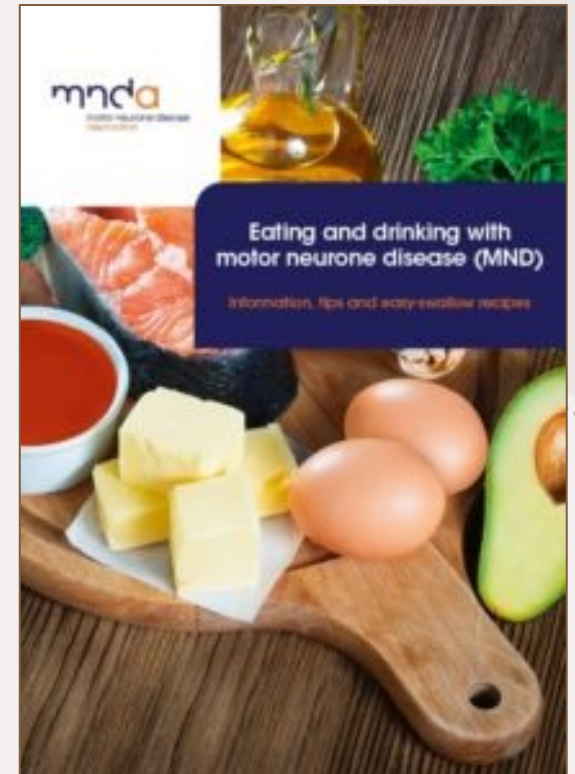
Assessment

- ♦ Weighing - regular weights, availability of different types of scales
- ♦ Dietary Recall – Food and fluid intake, compare with calculated requirements
- ♦ Consider appetite and thirst and strategies to overcome
- ♦ Gastrointestinal symptoms – nausea, constipation
- ♦ Causes of reduced oral intake - Upper arm weakness, swallowing difficulties, mood, recurrent chest infections



Food Fortification

- ♦ Increasing the nutrient and energy content of meal without increasing portion size
- ♦ Natural ingredients such as cream, butter, milk powder and cheese can be added to food to enrich
- ♦ Aim to eat little and often
- ♦ Aim to drink 6-8 glasses of fluid per day
- ♦ Avoid low fat, low sugar and diet food and drinks
- ♦ Nutritional supplements



Nutritional Supplementation

- Food First
- Oral nutritional supplements are widely available and come in various forms, such as drinks, powders, and desserts, providing additional nutrients and calories for those who may struggle to get enough through their regular diet.
- Should be recommended and prescribed by healthcare professionals to optimise dietary intake in a safe consistency.





Fibre Intake

- Constipation and bloating can be present in some people with MND. Consuming high-fibre foods can help manage these symptoms.
- Good sources of fibre include fruits, vegetables, whole grains, legumes, nuts, and seeds. Recommended target 25-30 grams of fibre per day.
- It's also important to drink plenty of water (6-8 cups or 1.5 -2L a day) to help the fibre move through the digestive system.
- However, if swallowing becomes difficult, it may be necessary to switch to softer or blended foods to ensure adequate fibre intake.

Ability to Eat and Drink



- ♦ The need for eating and drinking aids and altered utensils to help them take food from the plate to their mouth

Refer to Speech and Language or Occupational Therapist (OT)

- ♦ The need for help with food and drink preparation

Family/friends input or refer to social services

- ♦ Seek advice and aids for positioning, seating and posture while eating and drinking

Refer to physiotherapist, OT, wheelchair services

- ♦ dealing with social situations (for example, eating out)



Long Term Nutrition Support

- ♦ Introduce gastrostomy early where possible
- ♦ Take into account issues impacting nutritional status
- ♦ Consider ‘gastrostomy triggers’, such as ability to swallow, weight loss, respiratory function, effort of feeding and drinking and risk of choking
- ♦ Consider the person's preferences around longer term treatment option of tube feeding

Why do I need to think about tube feeding?

This guide focuses on eating and drinking by mouth, as much can be done to help with this, for as long as possible. However, with swallowing difficulties, you may need to think about other ways to receive the nutrition and fluids you need.

Significant weight loss with MND may affect other decisions. For example, having a feeding tube fitted is recommended before losing a lot of weight. It is your choice whether or not to have a feeding tube, but finding out the facts helps you make an informed and timely decision.



**For more detail, see our
Information sheet
7B: Tube feeding.**

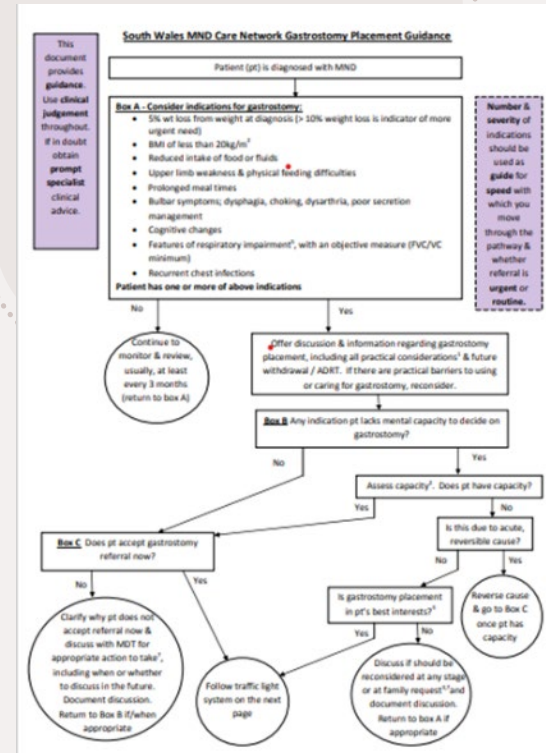
What is tube feeding?

You can use a feeding tube to receive specially prepared liquid feeds. The tube is inserted through the abdominal wall into your stomach, by a minor operation.

The most common method for long term tube feeding is called a gastrostomy. You may also hear this referred to as PEG, PIG or RIG – these terms are simply names for the way in which a tube is fitted. Whichever method is used, the result is the same.

Pre-Gastrostomy Assessment

- Visit at home – Often with a S< Colleague
- ProGAS study found PEG, RIG or PIG (hybrid) had similar outcomes
- Ideally placed when there is less than 10% wt loss from diagnosis
- Forced Vital Capacity (FVC) greater than 50% of expected
- Is the patient using Non Invasive Ventilation (NIV), will they need it during the procedure?
- South Wales MND Care Network does have Gastrostomy Placement Guidance



www.myMND.org.uk



Welcome to my myMND, a collection of educational resources for people living with MND/ALS



Supporting people to make choices around nutrition support and feeding tubes in MND/ALS

[Visit website >](#)



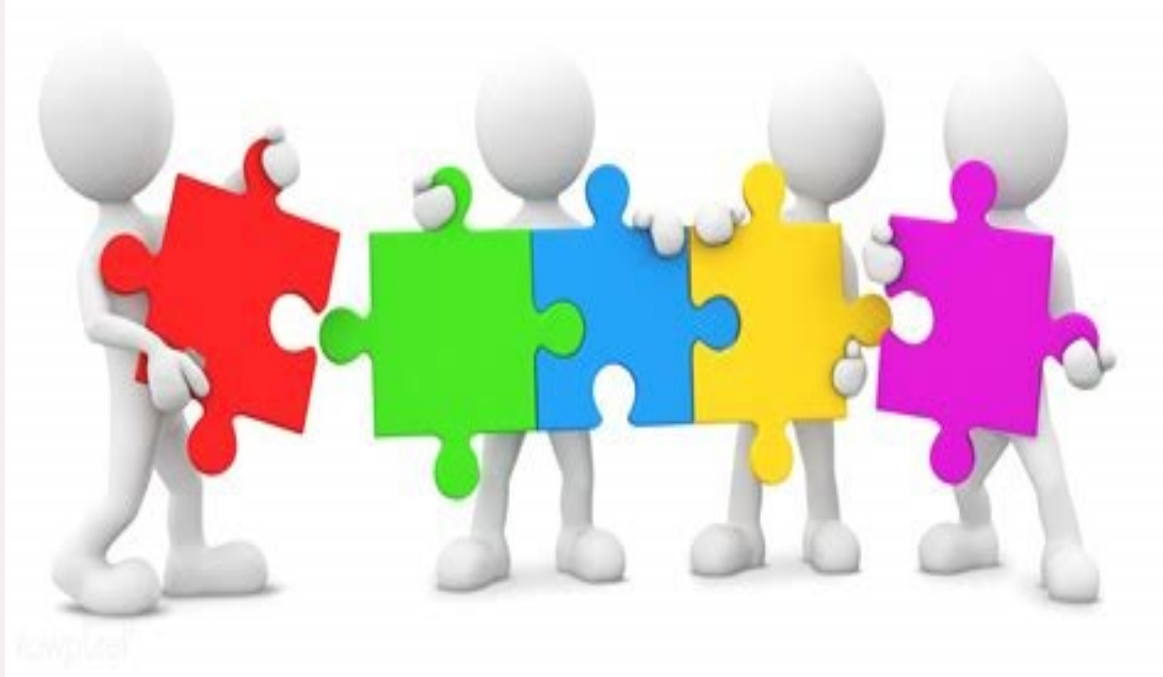
Supporting people to make choices around breathing support and ventilation in MND/ALS

[Visit website >](#)

Summary - Role of Dietitian

- ♦ Support patient's nutritional needs
- ♦ Assess diet, fluid intake and weight
- ♦ Suggest ways to optimise diet and nutritional intake
- ♦ Plan diet based around Speech and Language Therapist recommendations
- ♦ Provide information on tube feeding
- ♦ Monitor for any changes and consider appropriate timing for a feeding tube





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Thank you