My
Nutrition

# Eating and drinking with Motor Neurone Disease

This handout includes information for people with Motor Neurone Disease (MND) who are finding it hard to eat and drink.

MND causes muscles to weaken, including the muscles used for chewing, swallowing and breathing. This could make it more difficult to eat and drink, which you may notice as your disease worsens.

Currently, there is no evidence to suggest that a special diet, nutrient or food can cause or cure MND.

## What should I do if I find it hard to eat and drink?

- Make sure you speak with your MND Team, including the doctor, nurse, dietitian and speech pathologist if you have any concerns.
- If you are finding it difficult to eat and drink, below are some tips.

## 1. High protein high energy diet

- If you are losing weight without trying or are unable to eat enough, you can try a high protein high energy diet.
- For tips on this:
    - Search online for ‘Nutrition Education Materials Online’ (NEMO) Queensland Health website
    - Click on ‘Access the resources’
    - Select ‘Nutritional Support’ from the drop down box
    - Click on ‘**High protein / high energy diet’**
    - Direct link: https://www.health.qld.gov.au/__data/assets/pdf_file/0021/145830/nemo-hphe.pdf (written resource)

- Speak with your dietitian for more information.

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## 2. Texture modified diet

- If you are having difficulty chewing or swallowing, or are getting tired quickly when eating, your speech pathologist may recommend changing the texture of your foods and thickness of your drinks.
- Speak to your speech pathologist for more information.

## 3. Gastrostomy tube

- If you are finding it very difficult to eat and drink or are unable to eat and drink enough, a feeding tube may be an option for you.
- A special tube is placed in your stomach that lets you receive liquid nutrition, fluids and medications directly into your stomach.
- This tube could be called a ‘gastrostomy’, ‘PEG or ‘RIG’. You may still be able to eat and drink when using a gastrostomy tube.
- If you would like more information on this, speak with your MND Team, including the doctor, nurse, dietitian and speech pathologist. It is best to speak to the team early, as the decision to have a gastrostomy tube should not be left too late.
- For more information:
    - Written resource from Queensland Health: Search on ‘NEMO’ website: **Considering a Gastrostomy Tube?**
      Direct link:
      https://www.health.qld.gov.au/__data/assets/pdf_file/0026/154682/hphe_gastrostomytube.pdf
    - **‘myTube’ Videos**
      Short stories and demonstrations told by people with MND living with a gastrostomy tube
      Direct link: http://mytube.mymnd.org.uk/thinking

## Useful contacts

If you have questions, please contact your MND Team. These people may be from the community, local hospital or via your NDIS plan.

| MND team member | Phone number |
|---|---|
| Dietitian | |
| Speech Pathologist | |
| Nurse | |

This is a consensus document from Dietitian/ Nutritionists from the Nutrition Education Materials Online, "NEMO", team.

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