



Eating & Swallowing Changes

with motor neurone disease

This Booklet Covers:

- Eating & Swallowing Changes with MND
- Signs & Symptoms
- Reducing the Risk of Aspiration
- Strategies to Help
- Benefits of Checking in With Care Team Early
- Saliva Management

Why can Eating or Swallowing Abilities Change for Someone With MND?

Motor neurone disease (MND) affects the nerves responsible for muscle movement. If the muscles involved in eating and swallowing are affected, a person's ability to perform these actions may be compromised. Swallowing difficulties may also be referred to as 'dysphagia.' Below are examples of how changes in muscle function can impact eating and swallowing abilities:

Mouth Muscles

If the muscles of the lips, jaw, face, tongue and cheeks are affected, this can create difficulty with chewing food, and holding food and fluids in the mouth.

Hand and Arm Muscles

Someone with MND may also have reduced hand function. This can make it difficult for them to prepare food and feed themselves.

Neck Muscles

If the neck muscles are weak for someone with MND, they may not be able to hold their head up without support. This can therefore make it difficult to maintain a safe position to swallow food.

Throat Muscles

These muscles control swallowing which involves moving food from the mouth, down the throat to the oesophagus (food pipe), and onto the stomach. When these muscles are weaker, food, fluid or saliva can accidentally go down the throat towards the trachea (wind pipe), descending to the lungs.

When material enters the airway, this is called **aspiration** and can lead to chest infections, pneumonia, and be life threatening. There are lots of strategies that can be used to minimise the risk of aspiration, **covered later in the booklet.**

Signs and Symptoms of Eating and Swallowing Changes

Here are some common signs and symptoms that may suggest changes in swallowing and eating abilities. It is important to consult with a healthcare team as soon as possible if someone experiences any of the following:

- Coughing, throat-clearing or feeling short of breath during or after meals
- Chewing food is requiring more effort
- There is residue leftover in the throat after eating or drinking
- Unintentional weight loss
- Unexplained, recurrent chest infection

What is Aspiration and how to Reduce the Risk

Aspiration is when food, fluid or saliva goes into the lungs rather than into the stomach. Here are three key things someone can do to prevent serious complications from aspiration:

Clean Teeth at Least Twice per day

- Mouth bacteria, when aspirated, can result in a chest infection, such as pneumonia
- Cleaning the mouth reduces the amount of bacteria which may end up in lungs, if aspiration does occur



Practice Safe Swallow Techniques

How one eats and swallows can significantly influence their risk of aspiration. To minimise this risk, consider the following safe swallowing techniques:

- Sit upright, in a comfortable chair during all meals and snacks
- Keep the chin in a neutral position (avoid tilting the chin too far back or forward)
- Take smaller bites
- Eat slowly and chew each mouthful really well
- Swallow multiple times between mouthfuls
- Take small sips of fluid
- Avoid talking while eating and drinking
- If possible, schedule the main meal for when energy levels are highest
- Cook meals slightly longer to soften the food
- Cut food into bite-sized pieces
- Consider adding extra sauces or gravies to make food easier to chew and swallow

Keep a Food, Fluid and Symptom Diary

If there are any changes in eating or swallowing, it is helpful to record these symptoms as they occur. This information will be invaluable during a speech pathologist’s appointment to use in the assessment. Key details to note include:

- Date and time the symptom occurred
- Description of the symptom (e.g. coughing, food remaining in the throat)
- The type of food or fluid that triggered the symptom
- Relevant context, such as being out at lunch with friends or eating at home in front of the TV

 My food, fluid and symptom diary			
Date & Time	Symptom(s)	Food(s) or Drink(s) Consumed	Location & Company
12th April 10:30am	I coughed for 5 minutes	Stirfry with rice + lemonade	At cafe with friends
14th April 2:45pm	Food felt 'stuck' in my throat	Sandwich + cup of black tea	At home with wife

Other Strategies to Manage Eating and Swallowing Changes

There are many strategies which someone living with MND and their carer can try, if they start to notice changes in eating and swallowing ability, to optimise the mealtime experience. These include, but are not limited to:

Making Every Mouthful Count

For someone with MND, the effort needed to move the body can use a significant amount of energy. As a result, individuals with MND often have increased energy and protein needs to prevent weight loss. However, consuming large quantities of food to meet these requirements can be exhausting.

To address this, foods can be fortified and enriched by adding ingredients like butter, cream, oils, full cream milk, skim milk powder and nutrition supplements. This boosts the energy and / or protein content of each mouthful without requiring the person to eat a larger volume of food. *It's important to ensure that these ingredients do not alter the texture of the food prescribed by a speech pathologist. Always check with speech pathologist first if unsure.*



Look at the Eating Environment

- Play soothing music that the person with MND enjoys
- Create a calm space, with limited distractions
- Ensure a comfortable chair is available, positioned at the correct height for the table
- If needed, the carer can pre-chop foods before mealtime, allowing the focus during meal time to remain on eating

Plan Ahead When Going out for Meals

- Consider calling the restaurant or café in advance to request meal modifications if necessary
- If required, bring a portable blender to puree the food at the table
- Bring any adaptive cutlery, cups or aids with you



The Importance of Checking in With Your Healthcare Team Early

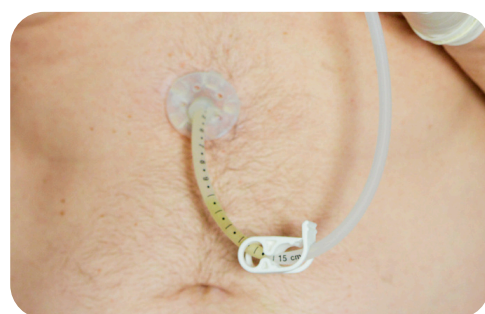
If you notice any coughing, throat clearing, or shortness of breath after eating, drinking, or even between meals (possibly due to saliva), it's important to contact your speech pathologist and schedule an assessment. Checking in with an occupational therapist (OT) and dietitian is also advisable for those experiencing difficulty feeding themselves or those noticing unintentional weight loss.

There are numerous strategies which can help assist someone with eating and swallowing changes. Here are a few strategies available which a health care team may suggest:

Percutaneous Endoscopic Gastrostomy (PEG) Tube

A PEG tube is a discrete feeding tube that is inserted directly into the stomach, allowing for nutrition and hydration to be delivered directly into the body. This can help alleviate the stress of meeting high energy and protein needs through eating and drinking alone, especially if there is some chewing or swallowing concerns.

There is a common misconception that a PEG tube is only necessary once eating and swallowing difficulties arise. In reality, it can be inserted as early as someone feels comfortable and allows the person with MND to become familiar with the tube and to "top up" their daily protein and energy intake as needed, under the guidance of a dietitian. This can help prevent additional weight loss and muscle wasting.



Additional Strategies to Discuss With Healthcare Team



Modified Utensils

If hand function is affected by MND, using cutlery with thicker, easier-to-grip handles (pictured), plateguards (pictured) or suction bowls that stick to the table can help make independent eating easier. There are many modified utensil options available, and exploring these with an OT team can be beneficial.

**image sourced from Amazon <https://www.amazon.com.au> - Food Guard for Plates*



Oral Nutrition Supplements (ONS)

These drinks and powders are specially formulated to provide additional energy, protein, vitamins and minerals into someone's diet. They are available in ready-to-consume forms and can also be mixed into meals to enhance their nutritional value. Consulting with a dietitian about whether these options are suitable can help ensure optimal nutrition.



Robotic-Feeder

A Robotic Feeder, like the Obi Feeder pictured, is a valuable tool for individuals with reduced upper limb function, who are unable to feed themselves. It features a robotic arm with a spoon that picks up food from a plate and brings it to the user's mouth. The device can be operated using any part of the body, which activates a switch. This can be a foot or head, for example. Funding for this device may vary depending on the individual's location, so it is important to consult with an OT to determine potential funding options and suitability. **image sourced from <https://meetobi.com/>*



Fluid Thickener

Fluid thickener can be used to thicken liquids, allowing them to move more slowly down the throat towards the oesophagus. This gives the body additional time to respond during swallowing. Consulting with a speech pathologist can help determine if using a thickener is necessary and safe for an individual's specific needs.

Saliva Changes

Individuals with MND may experience excessive or reduced saliva production and changes to saliva consistency. This may vary from person to person. Some may experience thick, ropey saliva which can be uncomfortable and difficult to clear. Others may experience dry mouth which is not easily relieved by sips of water. A speech pathologist can assist in managing the various changes to saliva and may recommend some of the following strategies.

Strategies for Saliva Management

- Frequent sips of fluid can help to clear the mouth of saliva
- If drooling is a concern, consider practicing swallowing your saliva before attempting to speak
- Some people find specific fruit juices to be helpful in breaking down saliva; eg. dark grape juice
- If experiencing dry mouth, your speech pathologist or medical team can guide appropriate over-the-counter dry-mouth products to relieve discomfort
- If unable to clear secretions by swallowing, discuss alternative solutions with your speech pathologist (eg. nebulisers, suction machines)

Want to Learn More? *Check out Carers Can!*

The “Carers Can” project, 2024 created a suite of videos and booklets like this one. The videos feature health professionals, MND Victoria staff members, carers and people with MND. They provides helpful strategies, lived experiences and other useful tips.

www.mnd.org.au/carers-can



Acknowledgements

- MND Victoria acknowledges the Traditional Owners and Custodians of the land on which this project was conducted. We pay our respects to all Aboriginal and Torres Strait Islander people and acknowledge Elders past and present.
- A special thanks to the allied health professionals and carers who were involved in the “Carers Can” Project
- The “Carers Can” resources were created by



and

PROUDLY SUPPORTED BY
FIGHT MND.

MND varies greatly between individuals. Always consult your healthcare team for a personalised plan. This resource was developed in 2024 by MND Victoria using information provided by allied health professionals working within the MND health sector.

The information provided is not intended to replace the expert care provided by Healthcare professionals.