

Introduction

Motor Neurone Disease (MND) can sometimes affect someone's ability to swallow. Quite often this difficulty might first show when swallowing clear thin liquids. If this happens it is essential to ensure that you can still eat and drink safely without food or drink going down the "wrong way".

Since a number of muscles are used to speak and swallow, the exact problems someone might experience depend on which muscles have been affected. However, if you experience swallowing problems it is important that you ask your family doctor for a referral to a speech and language therapist (SLT). Most SLTs know of MND and have expertise in assessing and managing swallowing problems. They can offer advice on swallowing strategies, diet and possible changes to feeding methods.

You may also want your GP to refer you to a speech and language therapist if you:

- Get tired during meals
- Take a long time to eat (longer than 45 minutes per meal)
- Lose weight
- No longer enjoy or are uninterested in eating

When swallowing problems occur it is common to find the person takes in less food and drink.

This can lead to:

- Weight loss,
- Dehydration,
- Loose dentures,
- Dry flaky skin,
- Reduced strength,
- Tiredness,
- Constipation, and
- Loss of well being.

Decreased fluid and energy intake can also be due to fatigue. So, addressing issues with eating and drinking by choosing alternative foods and methods of food preparation is important in the management of MND. The SLT and dietician on your healthcare team, along with your doctor, are major sources of advice for adapting to swallowing problems and maintaining good nutrition and hydration.

Which foods are found difficult can vary between individuals. Some people might find some difficult to swallow while others can manage the same foods well.

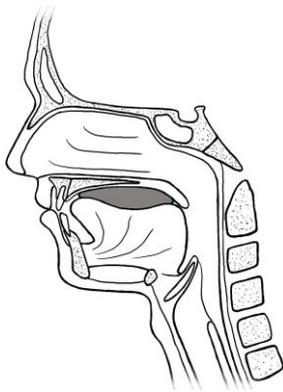
When the volume of food taken in is reduced it becomes important to make every mouthful count. So, when less is eaten it should contain as many calories and nutrients as possible. Most people will lose weight due to decreased calorie intake but in some cases people with MND may lose muscle and put on fat. If this happens to you it may be worth asking for the advice of a dietician.

MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.

THE MECHANICS OF SWALLOWING

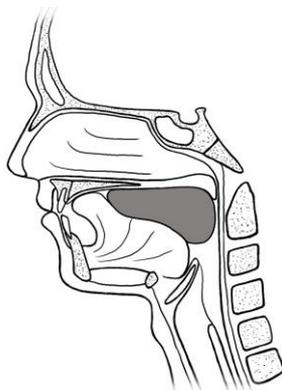
If your swallowing muscles are affected, your symptoms will depend on which muscles are weak. For example, if you have tongue and lip weakness you may have trouble keeping liquids sealed in your mouth until swallowed, or you might have trouble moving food around in your mouth. If your jaw muscles are more affected, chewing may be difficult or tiring.

The Four Phases of Swallowing

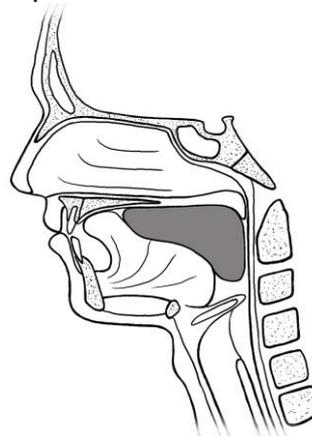


In phase-one, the food is chewed or "processed" in the mouth to form a mass or "bolus".

In phase-two, the muscles of the cheek, tongue, and upper throat move the food into the back of the mouth where the food triggers a reflex-like response causing the soft palate to rise to prevent food from entering the nasal cavity (nose). If these muscles are weakened, food may be difficult to move back in the mouth, or might enter the throat too early.

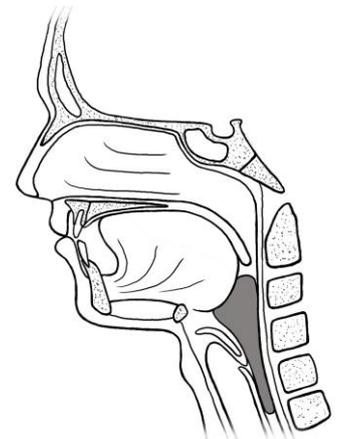


In phase-three the larynx (voice box) is raised, the tongue moves back and the airway entry is closed to prevent food from entering the windpipe.



In phase-four the muscles at the top of the oesophagus contract (people with MND may find that the lower muscles don't relax, in which case food gets stuck, feeling as if it is stuck in the back of the throat).

A final muscle contraction moves the food into the oesophagus toward the stomach.



SWALLOWING ASSESSMENTS

Swallowing assessments typically involve an inspection of your mouth, and observations of how you eat and drink small samples of food and liquid.

Sometimes you might be asked to swallow food and drink of different consistencies to determine which are easiest for you. During the assessment your SLT will note how you cope and will ask detailed questions about any foods and drinks that cause you to cough or clear your throat.

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Sometimes you might be asked to eat and drink small amounts of food and drink coated in barium so they can be seen on x-ray. This is helpful in identifying swallowing problems and testing "techniques" that may help you swallow more safely.

It can sometimes be useful for you to see a copy of your swallowing x-ray to give you a better understanding of what happens inside your throat when you swallow.

Common Swallowing Difficulties

Swallowing difficulties may include:

- Drooling,
- Coughing
- Throat clearing after a sip or bite
- Leaking of food from the mouth due to poor lip control
- Weak chewing and control of food in the mouth
- Difficulty moving food around the mouth
- Difficulty starting to swallow
- Food or drink escaping from nose area
- Unable to clear the mouth of food,
- Sensation of food caught or stuck in the throat
- Voice gurgling after eating and drinking,
- Difficulty swallowing thin liquids,
- Delayed swallowing reflex,
- Coughing and choking while eating and drinking,
- Unable to cough properly, and
- Tiredness when eating.

Making Eating and Drinking Safer

While eating can be one of the joys in life, it can be a challenging activity for some people with MND. People with swallowing problems are at higher risk of inhaling food or liquids and then

developing a kind of pneumonia called "aspiration pneumonia." Learn as much as you can about your own swallowing limitations and make sure your diet is adapted as your abilities change.

Change Posture

Sit upright in a firm chair with your head up and chin tucked in. Supporting your arms can also be helpful.

Take more time and be relaxed when eating

A person experiencing difficulty with eating and drinking may feel very embarrassed. While anxiety and upset may accompany embarrassment, anxiety itself impairs the ability to relax. Being relaxed and feeling confident is of tremendous assistance. Allow more time to eat meals and avoid rushing.

Concentrate on eating

Try to make sure there are **no distractions** like TV or radio while eating. If you find eating with the family or in a group is distracting, consider quieter meal times for yourself and one other person who can help you when needed. You can then simply use the family meal time to socialise and not worry about eating at that time. Do not try to combine eating with talking.

Focus on your eating position

If you have swallowing problems you should try to eat in an upright position. Sometimes your SLT will suggest you tuck your chin towards your chest to further protect your airway during feeding. There is also adapted feeding equipment which your occupational therapist (OT) may recommend for easier eating.

Adapt your cutlery and crockery.

A weak grip and limited leg movement can cause problems in positioning and holding plates, cups and cutlery. Use

items designed to make things easier to grip or manipulate. Some people have found attaching cutlery to a hand splint using Velcro to be useful. Other people have found that widening handles by adding stiff foam, like that used for pipe insulation, can help. The website www.livingmadeeasy.org.uk includes a range of specialist eating utensils.

Support your head

Weak neck muscles can cause problems in holding your head up while eating. A collar may help, though it may restrict swallowing. Other strategies include supporting your head by attaching it to a chair extension via a band around the head; or your carer could hold your head.

Find other devices to help

Some people who have difficulty in lifting food or drink to the mouth have found it useful to try the following:

- Use an adjustable cantilever table.
- Use a bed tray on top of the table.
- Mobile arm supports.
- Foot operated feeding devices.
- Powered feeding devices.
- Straws with one way valves.
- Specially designed cups.

Again, most of these items can be tracked down through the Living Made Easy website.

Palatal Training Devices

The soft palate must lift to allow you to swallow and prevent regurgitation of your food into the nose. If this becomes a real problem your speech therapist might suggest a palatal training device to help lift the soft palate. These devices can also sometimes help with nasal speech.

Dealing with problems

Learn what to do before an emergency happens. When the throat gets irritated

or blocked, it can close around the irritant making it difficult to breathe. Even your saliva can cause coughing and choking. This may also happen when a few small particles from a previous meal are still stuck in the throat.

Ideally every carer should take a First Aid course with special attention given to identifying and dealing with blockages to the airway. Knowing when and how to apply special manoeuvres to eject objects causing choking is important for carers of people with swallowing problems. Ask your MND care team specialist about this or contact your local Red Cross Association or St. Andrew's Ambulance branch for CPR and First Aid courses in your area.

Dietary Changes that Can Help

If chewing and swallowing problems develop it may be necessary to make changes to the texture of your food to help you cope with your changed eating abilities. Consult with your dietician, SLT, or doctor regarding changes to your diet.

When eating or drinking consider the following:

- Alcohol, such as a glass of wine or sherry, may help stimulate an appetite.
- Sipping an iced drink before the meal and between mouthfuls may be useful as this stimulates a stronger swallowing reflex.
- Take several smaller meals across the day as you may find this less tiring than one large meal.
- Allow plenty of time for the meal.
- Give yourself the opportunity to concentrate if need be.
- Do not rush, allow time to rest between courses.
- Garnishes can make food more appetising.

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- If a meal needs to be puréed, process the different items separately to retain their individual colours and flavours.

Take food and liquid separately

The swallowing muscles need slightly different actions to deal with solids and liquids. This can make it difficult for them to switch between eating and drinking.

When this is the case some people have problems with foods that have thin liquids mixed in with solids, like breakfast cereal and milk, or soup with meat or vegetables like Scotch broth. It may help to take in one consistency at a time. For example, take a sip of liquid and then a spoonful of solids. The same is true for foods with “skins”, like peas, sweetcorn or oranges, which have both a skin and soft or juicy centre.

Choose smaller and softer foods

To reduce chewing food should be softer and cut into smaller pieces. Since many people find their preferences for the consistency of their food varies from day to day, don't mash or purée food before it is really necessary. Food should be sufficiently bulky to be felt in the mouth yet not so large that it is difficult to swallow. Small bites will require less chewing before being ready to swallow

Foods and liquids to avoid

Avoid crumbly, dry or flaky foods like toast, crackers, crisps, pastries, fish in breadcrumbs and dry mashed potatoes. These and similar foods may be more difficult to manage due to their tendency to have loose and stray crumbs.

Moistening solids with gravy, sauces, milk, cream, butter, or soups, as appropriate, can make dry foods more manageable.

If you have problems with liquids, use straws with caution as it is possible for liquid to be brought up into the mouth at a higher speed and volume than might be safely swallowed. If food or drinks are too thin or runny, they may be harder to control in the mouth and escape into the airway before you are prepared to swallow them. This can cause distressing bouts of coughing.

Maintain Fluid Intake

It has been known for people to deliberately drink less in order not to have to go to the toilet too often. This will only bring many additional problems people with MND can do without. If trips to the toilet are causing problems speak to your OT or Care Team Specialist about how to get a potty or commode instead. To avoid dehydration you should introduce a lot of foods containing water in to the diet for example. sauces, soups and liquidised stews.

Thickening agents can be added to make liquidised puréed or runny foods easier to swallow. Cold foods high in water, but not runny, are easier to swallow such as fruit puree, yoghurt and mousses. Avoid foods which may turn to thin liquid in the mouth such as sorbets or commercial ice cream.

Many foods can be thickened to improve texture using, flour; cornflour or mashed potatoes. Commercially produced thickeners are also available. Speak to your GP, dietician, SLT or care team specialist to see which ones they recommend.

Although a blender can be useful in removing lumps in food it is recommended that the puréed food should be passed through a sieve to ensure that no lumps are accidentally overlooked.

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SWALLOWING SOLUTIONS: FOODS TO CHOOSE...	SWALLOWING PROBLEMS: FOODS TO LOSE...
<p>Custards, apple sauce, puddings, plain yoghurt Moist meats with gravy, add sauce, or soups to moisten Canned fruit, soft fruit (e.g., bananas) Eggs (scrambled, poached, NOT fried, and not omelettes) Cooked cereals (with milk) Macaroni cheese or pasta with sauce Milkshakes, frozen ice cream bars* Mashed potatoes with gravy Cottage cheese Salmon/tuna/egg moistened with mayonnaise or other spreads Thick, creamed or puréed soups Thick fruit juices, smoothies, tomato juice, vegetable juice</p> <p>* Avoid ice creams that go runny too quickly.</p>	<p>Extra-spicy, "hot" foods Acidic foods like pickles and some dressings Soft, doughy fresh bread Biscuits, crackers, dry cereal, digestive biscuits Dry muffins, cakes, scones Dry, fibrous, or bony meats and fish Fruits with tough skins Stringy fruits (e.g. pineapple, oranges, watermelon) Stringy vegetables (e.g. lettuce, celery, string beans, spinach) Fruits and vegetables with skin or seeds (e.g., peas, sweetcorn, apples, berries) Fried noodles, rice Popcorn, potato crisps, nuts Foods with small particles (e.g., nuts, seeds, coconut) • Sticky foods (e.g., peanut butter)</p>

Social Aspects of Eating and Drinking

It may become difficult for someone with swallowing problems to enjoy eating with others. The main problems some people encounter are:

- The time needed to eat and drink can increase,
- Food can go cold,
- Feeling pressurised to hurry,
- People may be embarrassed about making a mess,
- It can be difficult to relax, and
- People may worry about others' lack of understanding.

It can help to keep things relaxed, everyone will feel less anxious and eating together will soon become as enjoyable

as it was before dysphagia became a problem. Try and encourage others to adopt a flexible approach to eating styles. You might prefer to join others for a short while and finish the meal at a later stage to prevent tiredness or the food becoming cold.

Alcohol

It is not impossible to enjoy a drink when you have MND. However, people taking medication should always check with their GP or health visitor to find out if alcohol will have an adverse effect when taken with medication. People with a tube inserted into the stomach (gastrostomy) can even take alcohol through the tube in limited amounts.

Adapting How You Take Medication

Many people with MND have trouble

The information in this leaflet is believed to be accurate at the time of production, MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

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when swallowing medication. If you are having this problem you might consider asking your pharmacist if any drugs you get in pill form are available in liquid form instead, or if he or she could custom make a liquid suspension for you.

Additionally you could also ask your pharmacist which pills can be crushed if liquid forms aren't available. Only those identified as safe to crush can be ground using a pill crusher (available from your pharmacy) and mixed with a smooth, easy-to-eat food like apple sauce or yogurt to make swallowing easier.

Be aware that crushing is not recommended for slow release medications.

A dietician can make helpful suggestions about the following:

- Suitable methods of cooking
- Substitutions for suitable foods
- Ways to thicken thin liquids (for example, use commercial thickeners, or natural thickeners)
- Identifying semi-solid foods of a suitable consistency (e.g., pudding, custard, cottage cheese, puréed fruit)

Further Problems Reported by People with MND

Excess saliva can cause drooling and collection of saliva in the mouth, this can cause coughing and sometimes distressing coughing fits. Your GP or speech and language therapist should be able to give advice.

Many people lose fluid by being unable to swallow their saliva. This liquid is then lost from the body and may have to be

made up by extra fluid intake to avoid dehydration.

MND has been known to cause altered bowel function because of a change in diet, prescribed opioid drugs, dehydration or reduced mobility.

Medication, thrush, mouth breathing and insufficient drinks can cause a dry mouth.

Your sense of taste may alter, especially with a dry mouth. Foods with strong flavours (e.g. spicy foods) can cause coughing.

As ever, if you are bothered by any of the above side effects mention them to your GP or Care Team Specialist as most can be easily managed.

MAINTAINING GOOD NUTRITION

It can be challenging to maintain a fully balanced diet if you have chewing and swallowing difficulties. However, it is important to maintain good nutrition to enhance your strength and energy levels. Even though your activity level is low, your nutritional needs remain high.

There are many ways to add nutrients to food - this is not the time to worry about fat and cholesterol. In addition to special food supplements available in stores, there are many natural ways to supplement your food and drink for increased nutritional value. Please consult with your registered dietician for appropriate ways to maximise your nutrition. Drinking enough non-caffeinated liquids is extremely important for overall health as well as for energy.

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Additional Information

Factsheet 6	Feeding Tubes
Factsheet 30	Communication Strategies
Factsheet 34	Adapting to Swallowing Problems
Factsheet 35	Breathing Matters
Factsheet 36	Oral Health

MND Scotland Booklet, "Food Preparation for Swallowing Difficulties."

Website for Living Made Easy www.livingmadeeasy.org.uk/

MND Scotland wishes to thank Jane Woods for the illustrations included in this factsheet.