



9: Eating and drinking

This section can help you adjust if you have problems eating and drinking.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/publications

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



Living with
motor neurone disease

9: Eating and drinking



This section can help you adjust if you have problems eating and drinking.

Not everyone has the same symptoms with MND, but it can become more difficult to eat and drink enough if you have:

- swallowing difficulties (called dysphagia)
- problems with head and neck support
- problems with hand and arm control
- reduced mobility, which makes food preparation difficult
- fatigue, and eating or drinking takes a lot of effort.

This can lead to weight loss and affect your wellbeing. Weight loss can also happen in MND where muscles weaken and begin to waste.

You may also enjoy eating and drinking as a social activity. Yet, if it becomes harder to eat or drink with your usual control, you may feel self-conscious where food is involved.

“ Eating out is currently a major part of our lives and I would like to continue doing so, for as long as possible.”

Adapting the way you eat and drink can help you maintain a good diet and reduce anxiety.

Who can help me?

Your contacts are likely to include a:

Speech and language therapist (SLT) for assessment and guidance on eating and drinking techniques, and food consistencies for ease of swallowing (they often work closely with your dietitian).

Dietitian for guidance on food types, diet and how to stay nourished.

Occupational therapist (OT) for advice on posture and equipment if you develop weakness in your arms and hands.

Physiotherapist for advice on posture, exercise and assisted exercise.

GP for general medical advice, prescriptions and referrals.

Pharmacist for guidance if tablets are difficult to swallow, as medication may be available in liquid, soluble form or as patches.

Consultant gastroenterologist to discuss support such as tube feeding, for topping up or replacing meals and fluids.

See Tube feeding later in this section.

How will MND affect my eating and drinking?

MND can affect:

- how well you chew and swallow
- how much you are able to drink if this becomes difficult (or if you try to reduce how often you go to the toilet)
- how much you eat, if this becomes difficult or your appetite reduces.

Over a period of time, these effects may lead to a series of problems, such as:

- weight loss, feeling tired and loss of strength
- constipation from dehydration, change of diet or poor mobility
- loose dentures, or loose, dry and flaky skin, with a risk of developing pressure sores.

Some of these issues are directly linked to MND, so improving your diet will not eliminate them entirely. However, maintaining nutrition can help and is important for wellbeing.

“ I have difficulty opening my mouth wide enough to eat. Also, when I get food to my mouth, my tongue sometimes gets in the way.”

Swallowing

We rarely think about the way we swallow. It is a complex process, partly under our voluntary control and partly automatic.

Dysphagia is the medical term that describes problems with swallowing. With MND, this happens if muscles around the mouth and throat weaken.

This can cause some or all of the following problems:

- food and liquid may dribble out of the mouth
- poor chewing means food is not ready to swallow or positioned at the back of the mouth for swallowing
- each mouthful of food can take several attempts to clear
- a gag reflex, due to muscles not working well together
- food or liquid may ‘go down the wrong way’ into the lungs. This is called aspiration and may lead to a chest infection or pneumonia.

Some people also experience either thin saliva that pools in the mouth or thick stringy saliva that is difficult to clear. Combined with a weak cough this can be distressing, as saliva, food or liquids may cause coughing or choking. However, your physiotherapist, speech and language therapist and district nurse can advise on how to manage choking.

“ Drinking water was the first thing I noticed that triggered coughing. Now I have prescribed thickener in drinks.”

We provide an *MND Just in Case Kit* to help with breathlessness, anxiety and choking. This can be ordered by your GP, who prescribes medication to go inside the box to meet your likely needs. This is kept at your home in case a medical professional is called out of hours. Information is provided in the kit for visiting health professionals – and family carers, who may also be able to give you some of the medication. The kit can provide reassurance and many find it comforting to know it’s there, even though an emergency may never happen.

See [Further information at the end of this section about our resources.](#)

What should I eat and drink?

We are generally encouraged to eat less fat and sugar in our diets. However, with MND you may need food with higher calories. This is because MND can cause weight loss from muscle wasting or eating difficulties. Sometimes MND can also cause you to burn energy more quickly.

A dietitian can advise on supplements or how to fortify food if you need to increase calories. Often this can be done simply, by adding oils, fats or cream, but depends on your dietary needs. If you have another medical condition such as diabetes, or problems with thickened saliva, it is especially important to consult a dietitian.

There is no specific diet for MND, but a balanced diet includes a mix of:

Protein: for repair and regrowth

Eggs, milk, cheese, meat, fish, pulses, tofu, grains (such as oats or quinoa).

Carbohydrates: for energy and maintaining weight

Starch through: bread, rice, cereals, pasta, potatoes. Sugar through: jam, honey, syrup, chocolate.

Fat: for energy and to help the body absorb other nutrients

Butter, margarine, oil, dairy products, meat.

Vitamins and minerals: for healthy skin, eyes, bones, teeth and hair

Fruit, vegetables, milk, meat.

Fibre: for a healthy digestive system

Wholegrain cereals, wholemeal bread, fruit, vegetables.

Water: to prevent dehydration

Tea, soft drinks, fruit, vegetables, sauces, ice lollies, sorbets.

Alcohol

There is no reason to stop enjoying alcohol, if you wish to. It may cause coughing, but diluting drinks can help - you may need to add a thickener. In large amounts, alcohol can dehydrate the body or affect your balance. When taking any medication, ask your doctor if it is safe to continue drinking alcohol.

“ My husband liked his pint when going out and got really good at ways of drinking when he lost the use of his hands and arms.”

Consistency of food and drinks

Swallowing problems vary with MND. What may be easy for one person to eat, may be difficult for another.

Foods most likely to cause problems include:

- mixed consistencies, as with some soups or cereals
- foods that need a lot of chewing, such as raw vegetables and some meats
- stringy food, such as runner beans
- coarse hard food, such as nuts
- foods that get sticky in the mouth, like bread or mashed potato
- vegetable skins, which can be difficult to clear from the roof of the mouth
- crumbly foods like biscuits, cakes and crunchy cereals.

Spicy or sharp foods can help stimulate saliva to ease swallowing, but can make you cough.

“ Any food that’s flaky, powdery, crunchy, or that needs to be chewed a lot, is a food to avoid.”

Experiment and try to:

- select foods that are the right consistency for you
- cook meat and vegetables until tender, and break up or mash
- moisten food with gravy, custard and sauces (sweet and savoury)
- soften hard foods (dunk biscuits or spread butter thickly on hot toast)
- peel and stew hard fruits like apples
- use a blender to change the consistency of foods.

“ Some companies deliver ready meals to people’s homes, including puréed meals which look attractive and appetising. Once you discover these, it saves a lot of preparation time. They may seem expensive, but there’s no waste involved.”

However, try not to mash or purée foods sooner than necessary. Your ability may vary on different days and it’s important to keep biting and chewing as long as you can. This helps keep the tongue mobile.

You can be assessed by a speech and language therapist, for advice on food and drink that will enable you to swallow most safely.

Using thickeners

The Eatwell Guide, by Public Health England, recommends we drink 6-8 glasses of fluid every day.

However, liquids can cause more difficulty than solids, as thin drinks are hard to control. Semi-solid foods (like porridge) are the easiest to swallow.

An early sign of swallowing difficulties may be coughing when drinking. Even a tiny amount ‘going the wrong way’ can make you cough. If this is happening, ask your GP for a referral to be assessed by a speech and language therapist. They can advise and may recommend thickened fluids.

Try thicker fluids or foods with a high fluid content such as:

- milk shakes, fruit purées and homemade or bought ‘smoothies’
- yoghurt, custard, mousses, jelly or ice cream
- smooth soups.

Add thickeners to food and drink, such as:

- flour, cornflour, arrowroot, rice flour, ground rice or semolina
- instant mash potato
- breadcrumbs or crushed cereal that mixes easily (eg powdered oats or wheat biscuits)
- powder prescribed by your GP to add texture or thicken.

Water adds moisture to food, but thin juices can be tricky to swallow. Add oil, butter, cream or yoghurt to moisten food and add calories too.

“ Lots of cream, yoghurt, creme fraiche, sauces or gravy make foods easier to swallow.”

What can I do to make eating and drinking easier?

Always talk to your health and social care team about any problems with eating and drinking. The following suggests some potential solutions to common concerns:

I tend to regurgitate food or experience reflux (acid or heartburn):

Eat small portions more often, rather than large meals. Try to sit upright for half an hour after eating. Avoid foods that tend to cause acid, such as spicy or acidic foods. Ask your GP about medication.

I find it difficult to eat and socialise at the same time:

It can be tempting to rush through food in order to join a conversation, but take your time if you have swallowing difficulties. Some people prefer to eat separately and just share a few mouthfuls with others, so they can focus on being sociable.

I get very tired and eating takes a long time:

Try several small meals rather than one large one. If it takes a long time to eat, an insulated plate helps keep food warm.

“ I divide his meal between two plates, one of which is covered and kept in a warm oven, so that his food won't get too cold.”

Chewing and swallowing are becoming more difficult:

Small mouthfuls are usually easier to manage. Swallow each one before taking the next, as the swallow clears the throat as well as the mouth. Sometimes you may need several swallows to clear each mouthful.

Straws are useful for drinking, but it's more difficult to suck:

Ask your speech and language therapist and your dietitian about adapted straws with one way suction, where a valve prevents the fluid from slipping back down the straw. However, with swallowing difficulties using a straw may increase risk of aspiration (fluid 'going down the wrong way' into your airway or lungs).

I like food to look good:

Attractively presented meals can help stimulate the appetite. If food needs to be blended, keep flavours and colours separate (rather than combining everything). Shaped food moulds can be bought from shops and online, to make puréed food look more appetising.

I find it difficult to grip utensils and sit correctly:

Your occupational therapist and speech and language therapist can advise about posture and equipment, such as arm supports and adapted utensils.

“ Avoid combinations of different objects where one will do, such as a cup and saucer, or a knife and fork.”

Taking medication is very difficult:

Some tablets can be crushed and mixed with soft foods to make them easier to swallow, but not all. Check with your GP or pharmacist. They can also advise on liquid medications, patches, suppositories or drugs that dissolve under the tongue.

My sense of taste has altered or disappeared:

This happens for a small number of people with MND. Strong, spicy or acidic flavours can help, unless they make you cough. Taste can be affected by thrush or sticky saliva coating the mouth. Ask your GP for advice.

I have a very dry mouth:

Discuss with your GP, as some medications can cause a dry mouth. Artificial saliva sprays and gels may help. You can get dehydrated if you don't drink enough, so increase your fluid intake, with thickeners if necessary. Small sips of very cold water or ice cubes on sticks can help.

I keep hurting my cheeks, mouth and tongue:

If your facial muscles weaken, you may bite or burn the insides of your mouth by accident. Seek advice from your speech and language therapist for guidance on techniques to avoid this.

“ Avoid serving food that is very hot. If you cannot move food about easily, it can burn the tongue, gums or roof of the mouth.”

We eat at different times, or separately:

Discuss this with your partner or family to clear concerns. You may be anxious about changes to the way you eat. Those close to you may feel guilty about eating things that you find difficult. It is important that you all eat well, including your carer, as they may neglect their own needs when focused on supporting you. Maintaining social contact over meals can be valuable.

“ We ate at different times. When I was trying to eat mine at the same time, he would tap the table to say that he was ready for the next mouthful, so in the end it was easier to have mine after his.”

I worry about mouth care:

Ensure that all food has been cleared from the mouth at the end of a meal. Clean teeth thoroughly, at least twice a day. If this becomes difficult to do, an electric or long angle-headed toothbrush may help, with a small amount of low foaming toothpaste. Electric toothbrushes also make it easier for carers to support you with this.

Have regular dental checkups and ask about alternative ways to clean your teeth if needed (some dentists may make home visits).

See Further information at the end of this section about our resources on mouth care and dental support.

Tube feeding

If you begin to have problems with eating and drinking, ask your health and social care team for a referral to a specialist in tube feeding (known as enteral feeding). They can assess your needs and discuss the options. You can then make an informed decision whether or not you wish to use this.

Two methods of tube feeding can be used:

- nasogastric, where a narrow feeding tube is passed through the nostrils, down the back of the throat and into the stomach
- gastrostomy, where a feeding tube is inserted directly into the stomach through the abdomen.

The most popular method for long term use is a gastrostomy, which is offered in three forms:

- PEG (Percutaneous Endoscopic Gastrostomy)
- RIG (Radiologically Inserted Gastrostomy)
- PIG (Per-oral Image Guided Gastrostomy).

The difference is how the tubes are inserted, but the end result is the same. Once the tube is fitted, you can use it to have specially prepared liquid feeds.

“ Tube feeding can be helpful for taking medication.”

With a gastrostomy:

- the feeding tube is hidden under your clothes
- you can still eat and drink by mouth after having a tube fitted, for as long as you feel safe or wish to do so
- you can either top up your diet, or receive all food and fluids through the tube
- the special feeds are provided on prescription and delivered to your home, including high calorie feeds if you have lost weight
- your dietitian can assess your needs, prescribe feeds and advise on timings

- you may have an improved sense of wellbeing as your energy levels increase
- each tube generally lasts up to 12 months and can be easily replaced, some types of tube can last much longer.

Always ask a relevant member of your health care team before using anything other than a fluid or special feed through a tube. This is to avoid risk of blocking.

Anxiety about meals should lessen with tube feeding. Your carer or partner is also likely to feel more confident that you are receiving the food and fluids you need.

“ With a feeding tube, I’m feeling much better now I don’t have to struggle (or eat more yoghurt than I ever imagined to get my pills down). I had no idea how easy tube feeding would be and how difficult it was to stay hydrated without it...my appetite has returned now that I’m hydrated.”

If you use tube feeding for most or all of your food and drink, it reduces the risk of food or drink entering the airway when swallowing, which can cause chest infections.

Whether to have a feeding tube is your choice, but works best before any major weight loss. You may prefer to carry on as you are, with advice from your dietitian and speech and language therapist. Discuss the options with them, and with your family.

This can be a good time to talk through other treatment decisions, even if not needed yet, so you can make informed choices in a timely way.

Sometimes your wishes may be different to those of your family or friends. Open conversation will hopefully bring you to a shared understanding and views can change over time.

You may have a tube fitted later, or decide to stop using one at some point. Again, discuss this with your carers, family and healthcare team.

See *Further information at the end of this section for resources and, when ready, Section 11: Planning ahead.*

Changes in bladder and bowel habits

You may find it more difficult to get to the toilet or remove clothing if you have mobility problems. However, in most cases, MND does not directly affect the muscles that control the bladder or bowel. This means any changes should be investigated, as they may not be due to MND.

You may experience changes due to:

- not having enough food, liquid or fibre
- some types of medication
- reduced mobility, leading to weakness of the pelvic floor, abdominal muscles or diaphragm
- weakened breathing, which can reduce the strength of ‘push’ needed when you try to poo
- tube feeding, which may cause constipation or diarrhoea until you adjust.

It may help to:

- eat more foods containing fibre
- increase your liquid intake
- talk to a physiotherapist about assisted exercise
- ask your dietitian, GP, district nurse or pharmacist for advice.

If your bladder or the way you pee is affected, it may be due to irritation from:

- concentrated pee, due to drinking less
- citrus drinks, such as orange and pineapple juice
- alcohol or caffeine (tea and coffee).

It may be tempting to reduce the amount you drink if it takes effort and time to get to the toilet, but it is important to keep well hydrated.

Key points

- Even if you feel tube feeding may not be right for you, find out about it as soon as you can. Your views may change as you find out more, or as your needs progress.
- Discussions on eating and drinking can be quite detailed, so try to explore all options early in case you experience any problems with speech and communication later on.
- Good nutrition is important, but eating and drinking are about enjoyment as well as health. Select the flavours, amounts of food and times of meals that suit you best.

Further information:

From our range of information sheets:

1A: *Nice guideline on MND*

7A: *Swallowing difficulties*

7B: *Tube feeding*

11B: *Mouth care*

11C: *Equipment and wheelchairs*

From our guides and other publications:

Eating and drinking for people with motor neurone disease: guidance on problems with eating and drinking and a range of easy swallow recipes.

Caring and MND: support for you: a comprehensive guide for carers.

Caring and MND: quick guide: summary information for carers.

Information to pass to your health or social care professionals:

P3: Managing saliva problems in motor neurone disease

P8: Dysphagia in motor neurone disease

Motor neurone disease for dental professionals: a guide to help dentists support people with MND

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at:

<https://forum.mndassociation.org>

myTube:

For information and video content about tube feeding, featuring people with MND and their family and carers, see

<http://mytube.mymnd.org.uk>

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**This resource has been evidenced,
user tested and reviewed by experts.**

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