Eating & Drinking

"I was aware I had lost weight. Continuing on a low fat, low sugar diet was not suitable any more"

Good nutrition is important for us all. Staying well nourished is one of the most important ways of countering the effects of MND.
In addition, for many of us sharing meals and drinking with others are two of the most enjoyable social activities. When swallowing goes wrong you can't eat, drink or even swallow saliva with your usual control. Far from being a pleasure, food becomes a negative part of your life. You may feel like avoiding these social events for fear of embarrassment or offending others.

So, getting eating and drinking right will help you be less anxious, maintain a nutritious diet and join in.

The topics covered in this section are:

- Nutrition
- Swallowing and what happens when it goes wrong
- What kind of help is available
- Some other symptoms associated with eating and drinking

Nutrition

Staying well nourished

There is no 'special diet' for MND. The best general advice is to eat a varied and balanced diet, taking care to include enough fibre and liquid.

A balanced diet should include:

Nutrient		Found in	Why Needed
Protein		Eggs, milk, cheese, meat, fish, pulses	For repair and growth
Carbohydrates	Starch	Bread, rice, cereals, pasta, potatoes	For energy & maintaining weight
	Sugar	Jam, honey, syrup, confectionary, soft drinks	
Fat	Saturated / Trans Fat	Butter, lard, visible fat on meat & poultry, processed meats, cheese, confectionary, takeaway foods	For Energy – High in calories, Fat soluble vitamins, Essential fatty acids
	Unsaturated (monounsaturated / polyunsaturated)	Vegetable oils, dairy spreads made from these oils, nuts, lean meat & poultry, oily fish	
Vitamins & minerals		Fruit, vegetables, milk, meat	For healthy skin, eyes, bones, teeth, hair
Fibre		Wholegrain cereals, wholemeal bread, fruit, vegetables and pulses beans, peas, lentils	For a healthy digestive system
Fluids		Water, fruit juice, fruit, vegetables, sauces, limited tea and coffee	To prevent dehydration

MND affects nutrition in several ways:

- Reduction in physical activity results in loss of muscle tissue and an increase in body fat
- Problems with chewing and swallowing result in less food being eaten, which in turn results in loss of muscle and body fat
- Muscle tissue wastes when it has lost its motor nerve supply and when it doesn't get enough nourishment, so it is even more important to nourish remaining healthy muscle

Consequences of poor nutrition

When swallowing becomes difficult, your natural reaction might be to eat and drink less and to avoid foods which cause problems. If your mobility is affected you might be tempted to cut down on drinks to reduce the number of trips you need to make to the toilet.

Over a period of time, this may lead to a series of problems:

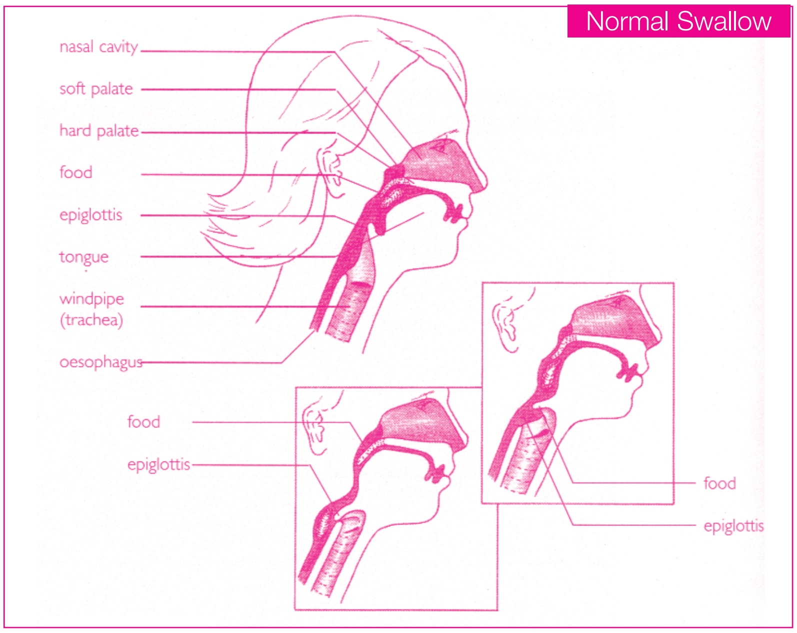
- Weight loss
- Decreased energy levels, weakness, tiredness
- Poor immune system – more susceptible to infections and less able to fight infections if they occur
- Constipation
- Dehydration - Skin becomes loose, dry, flaky so there is a higher risk of developing pressure sores
- Sore mouth due to poor oral hygiene, infections or ill fitting dentures

Some of these symptoms can be caused by MND itself, so improving your diet will not eliminate them entirely, but you should experience a definite improvement and greater well-being.

Swallowing

What is a normal swallow?

Swallowing is one of those things that few of us rarely think about. It is a complex process, partly under our voluntary control and partly automatic.



Stages in a normal swallow:

- Food or drink is taken into the mouth. The lips need to seal to keep food and drinks in the mouth for swallowing
- It is chewed to form a ball and moved to the back of the mouth using the lips, jaw and particularly the tongue
- It moves towards the throat and muscles contract to start to push the food down
- The voice box rises to close the opening into the airway & lungs and to open the entrance into the gullet (oesophagus)
- As the food reaches the oesophagus (gullet), it relaxes and muscles push it through to the stomach.

  Many muscles are involved in a single swallow

What happens when things go wrong?

Dysphagia is the medical term used when the normal eating and swallowing process goes wrong.

Some of the causes include:

Potential Difficulty	Cause	Result
Lips unable to create seal	Weakness in muscles around the lips	Food and liquid may dribble out
Chewing	Weakened jaw muscles	Food not prepared for swallowing
Moving food around the mouth	Weak tongue	Food not collected and swallowed
	Weakened throat muscles	Several attempts are needed to clear each mouthful
Food reaches airway before it has closed	Swallowing is delayed	Food/liquid trickles into lungs. Chest infections
Soft palate not raising to block off nasal cavity	Weak soft palate	Sneezing or nasal regurgitation when eating/drinking
Poor co-ordination of weakened muscles produces gag response		Coughing and choking
Weakened chest (breathing) muscles		Difficulty with coughing
Thick ropy saliva		Makes it difficult to swallow and clear mouth

What kind of help is available?

Where to go for Help

- **Speech & language Therapist**

  Is an expert in the function of the mouth and throat. This includes eating and drinking as well as speech and communication. S/he will teach you techniques to help you eat and drink as safely and efficiently as possible

- **Dietitian**

  A Dietitian will ensure that your dietary needs are met by assessing your nutritional requirements and monitoring your food and fluid intake. S/he will work closely with the Speech & Language Therapist to provide information on a modified consistency diet if needed

- **General Practitioner**

  Gives medical advice and can prescribe treatments. You may need a referral from your doctor to access some therapy services

- **Pharmacist**

  Can advise about the best types of medication in particular circumstances. For example, many medications can be dispensed in liquid form

- **Occupational Therapist**

  Can advise about posture and equipment to help you continue to feed yourself if you develop weakness in your arms and hands

Here are some suggestions to help you stay well nourished:

Consistency of foods

Difficult foods to swallow vary widely from person to person - some people cannot eat toast, others can eat toast but not jelly.

In general, liquids cause more difficulty than solids, and food of a semi-solid consistency (like porridge) is the easiest to swallow. Experiment to find the consistency that suits you best:

- Try to use foods that are already the right consistency for you
- Cook meat and vegetables until tender so they can be broken up more easily in the mouth, or with a knife
- Moisten food with gravy, custard and sauces (sweet and savoury)
- Soften hard foods (e.g. dunk biscuits, spread butter thickly on hot toast)
- Hard fruits like apples are best peeled and stewed

The IMNDA has a recipe collection available giving ideas for easy to swallow meals and information on food supplements and catering services in selected areas of the country.

Mashing and pureeing foods

Don't do this sooner than necessary. You may find you can cope with different consistencies on different days. It is important to keep biting and chewing for as long as you can because moving the jaw helps to keep the tongue mobile and play its part in helping you to swallow.

A hand or electric blender is very useful and may make it possible to continue to eat your favourite dishes by changing the consistency of foods that are difficult to swallow.

It is important to remember that, adding water to food will increase its volume. It will still only contain the same amount of energy, protein, vitamins and minerals. It may be necessary to add extra butter, cream, milk, mayonnaise, high calorie gravies and sauces to these foods to increase their nutritional value. This is called food fortification.

In recent years we have all been encouraged to eat less fat and sugar to reduce the risk of heart disease and cancer. When you have MND the most important thing is to stay well nourished. So eating these foods is often the most practical way of doing so.

If you need a special diet for another medical condition such as diabetes, coeliac disease or lactose intolerance it is especially important to consult a Dietitian.

Consistency of liquids

We all need to drink six to eight cups of liquid a day and swallowing muscles need to be finely tuned to cope with fast flowing clear liquid. One of the first signs of developing swallowing difficulties may be coughing when drinking plain water. Even a tiny amount of water 'going the wrong way' will make you cough.

- Sip fluids before or after meals
- Try to avoid talking when drinking
- Sit up straight when drinking – do not drink when lying down
- A volume control beaker can help swallowing fluids. Just over 5 or 10ml volumes are released at one time by these beakers. The smaller volume can improve safety of swallowing
- Changes in posture can help swallowing. Tucking the chin down towards the chest can help to block off the airway when swallowing drinks. Similarly, turning the head to the left/right can help food to pass through the throat more easily

Changing the consistency of liquids and food

Try:

- Milk shakes
- Fruit purees - home made or bought ‘smoothies’
- Foods with high liquid content such as yoghurt, custard, mousses, jelly or ice cream are other ways of getting enough fluid
- Thickeners (added to food and drinks)
  - Flour, cornflour, arrowroot, rice flour
  - Ground rice, semolina
  - Instant mash potato
  - Breadcrumbs
  - Cereal flakes (e.g. Weetabix)
  - Commercially produced thickener (e.g. Thick N Easy, Nutilis)
- When adding a thickening agent to a drink, make sure to add the amount recommended by your Speech & Language Therapist
- Where possible, mix the thickening agent into the drink with a whisk and leave to stand for 60 seconds

Foods to avoid

Foods most likely to cause problems include:

- Mixed textures and liquids with bits in e.g. Minestrone soup
- Foods that need a lot of chewing e.g. fresh bread, vegetable skins
- Stringy food e.g. such as bacon, old green beans
- Coarse hard food e.g. such as nuts, hard toast
- Foods that get sticky in the mouth e.g. bread, mashed potato, white rice
- Raw vegetables and salads. Some cooked vegetable skins e.g tomato can be difficult to clear from the roof of the mouth
- Crumbly foods like biscuits, cakes and crunchy cereals

Sharp or spicy foods can increase the flow of saliva for some people, whilst others find that the strong stimulation of these foods helps swallowing.

Changes to mealtimes

Try to eat at the table in a relaxed, quiet atmosphere. If you are regurgitating food or have difficulty in clearing your mouth effectively it can help to remain sitting upright for half an hour after a meal.

Concentrate on eating - don’t feel you have to hurry up and swallow before joining the conversation. Some people prefer to eat separately and just share a few mouthfuls with others – then you can concentrate on being sociable. If you are planning a meal in a restaurant, ask to be seated in a quiet corner.

You may find it less tiring to have several small meals rather than one large one. If it takes a long time to eat, an insulated plate will keep food warm.

Small mouthfuls are usually easier to manage - swallow each one before taking the next. Sometimes you may need several swallows to clear each mouthful - the swallow clears the throat as well as the mouth. Attractively presented meals can stimulate the appetite. If foods need to be liquidized blend each food separately to retain their colours and flavours. Food moulds can improve the presentation of your meals to make them more appealing.

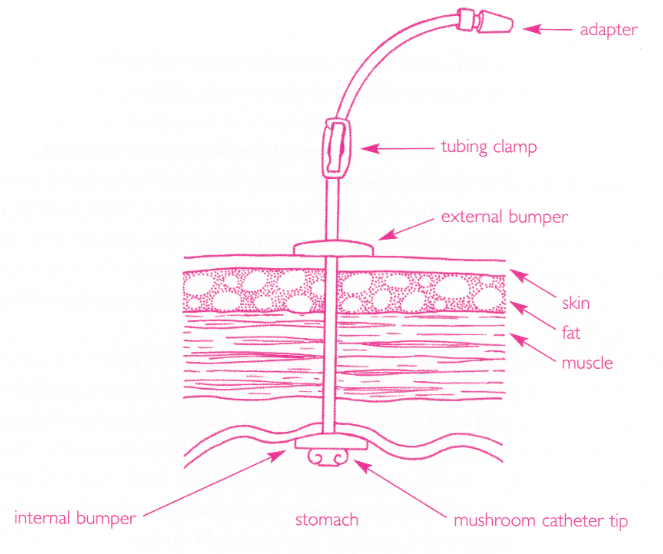
Other problems that may affect eating

Weakness in the muscles in your neck, shoulders, arms and hands may affect your posture and your ability to feed yourself. Your Occupational Therapist and Speech & Language Therapist can advise about posture and equipment that can help. ➜ See ‘Everyday Activities’ section for more information.

What if I am still not getting enough to eat?

If you begin to lose weight or if your appetite is very poor, your Dietitian may advise you take some oral nutritional supplements. These supplemental drinks are concentrated sources of energy, protein, vitamins and minerals. They are not intended to replace your meals but to supplement your intake. These products are available through your local pharmacy on prescription. There are many different types i.e. milk style, juice style, soup style, yoghurt style, high energy puddings & milk shakes, energy/protein supplements and there are also several different flavours available.

PEG



Alternative feeding methods

These may be suggested to you:

Nasogastric feeding

This is usually done as an emergency and involves passing a narrow tube down the nose and into the stomach. It is generally for short-term use because the tube is visible and can cause nasal ulceration. It is unlikely that this method will be suggested as a long term feeding method.

Gastrostomy

This is known as **PEG**
(percutaneous endoscopic gastrostomy)
or **RIG** (radiologically inserted gastrostomy).
The difference is in the way the tubes are inserted; the end result is the same.

PEG or **RIG** feeding is more suitable for people who need nutritional support over a longer period of time. A minor operation is performed to insert a small feeding tube through the abdominal wall into the stomach. This can be discreetly hidden under your clothes.

“I resisted **PEG**, I wanted to fight the disease, and not accept defeat. I believed that a liquid feed through a tube couldn’t be as beneficial as a ‘healthy diet’. This proved to be wrong on both counts. I was surprised at the ease of the process. By removing so much stress, my **PEG** has greatly improved quality of life for me and my family.”

The benefits of gastrostomy feeding

Difficulty swallowing can become distressing for all concerned. **PEG** or **RIG** feeding can remove the anxiety, which often accompanies meals and allows you to get all the nutrition you need from a specially prepared liquid feed. **PEG** feeding may reduce the risk of chest infections, which can result from small amounts of food and/or fluid entering the airway during swallowing.

You should also have an improved sense of well being as your energy levels increase.

If you have lost a lot of weight your Dietitian may prescribe a high calorie feed to help you regain some of it. After this, the type and amount of feed will be adjusted to help keep your weight at the right level for you.

Many people with MND have trouble with their bowels. The reasons for this include weakened pelvic floor muscles and poor fibre and/or fluid intake associated with swallowing difficulties. It can take a while for the bowels to get back to a normal pattern and your Dietitian may advise the use of a special feed with extra fibre if constipation is a problem.

Continuing to eat and drink with a gastrostomy

Many people with MND continue to take some foods and/or drinks by mouth after a PEG has been fitted. You may even enjoy them more because you can eat just small amounts and only the foods you like without having to worry about getting enough to eat.

Your speech & language therapist will advise you about what is safe for you and what types of food and drink are suitable.

Bathing and showering with a gastrostomy

For the first four weeks after the tube is fitted it is advisable to only shower or wash. After that it is fine to have a bath. Make sure to close the tube before hand and to carefully dry the tube and exit site afterwards.

You can go swimming too. Follow the same procedure as for bathing.

When to start thinking about a PEG

It is better to think about a PEG before considerable weight loss has occurred and before you are at risk of chest infection due to aspiration (inhalation) of food into the airway.

Before making a decision you should discuss it with your family, the Dietitian, Speech & Language Therapist and Doctor.

Making the decision

The decision is yours. You may prefer not to be fed by tube, but to continue the way you are, discussing any other problems with the Dietitian and Speech and Language Therapist.

To help you make the decision ask questions of the professional staff who help with your care, gathering information that will clarify things for you. This is also an opportunity to talk about feeding in the later stages of the disease as well as discussing dietary problems affecting you now.

When you have made up your mind, you may find that the decision you make is not the one that relatives and carers would like. Talking together will hopefully bring you to a shared understanding.

As your MND progresses you may change your views on feeding. You may then wish to have a tube inserted or, if you have had one, you may decide to discontinue using it. Again, discuss this with your carers and family.

➔ See Living Wills in ‘Planning Ahead’ section.

It is important to remember that your views and wishes will be respected.

What happens when you have a PEG

PEG (Percutaneous Endoscopic Gastrostomy)

The procedure requires a minor operation and is usually inserted under a local anaesthetic or a light general anaesthetic at your local general hospital.

- An endoscope, a flexible instrument used to examine inside the stomach, is passed down into the stomach and, after the area has been anaesthetised, a small incision made
- A guide wire is inserted into the incision from the outside
- The guide wire is brought up through the endoscope to be returned to the stomach with the feeding tube attached
- The tube is prevented from moving by a small plastic disc
- A cap is placed over the end of the tube when feeding is not taking place

The whole process takes about 30 minutes to complete and you will be drowsy or asleep whilst it is happening. If there is any discomfort after the operation you will be given medication to help.

“I was surprised at the ease of the whole process. On awakening after sedation the tube was in place with no pain and it seemed almost natural rather than invasive. Pouring liquid feed down the tube, flushing with water and cleaning very quickly became part of the daily routine. It doesn’t disrupt or prevent any activity.”

“The feed prescribed by the nutritionist contains all the energy, protein and nutrients of a well balanced diet. It is maintaining my weight and I feel well.”

RIG (Radiologically Inserted Gastrostomy)

- A fine, soft nasogastric tube will be put down the nose into the stomach
- A liquid which shows up on an X-ray may be fed down the tube into the stomach, this will allow the doctor to see the large bowel which must be avoided during the procedure
- On the day of the procedure, air will be put into stomach using the nasogastric tube - the air moves the stomach into the right position
- A local anaesthetic is injected into the skin and a small incision made. The gastrostomy tube is then inserted directly into the stomach, under X-ray guidance
- Up to four stitches (called T-fasteners) are used and are removed after 10 to 14 days
- The nasogastric tube is removed

The process takes about an hour.

The type of food you will be given

Your dietician will recommend a specially prepared liquid feed, containing all the nutrients, protein, energy, vitamins and minerals you need each day and the most suitable method and timescale of feeds for you.

The special feed is provided by your local hospital or on prescription and will be delivered to your home.

Should extra fluids need to be added to your tube your Dietitian or Public Health Nurse will advise you. Liquidised or pureed food should not be passed through the tube as this could cause the tube to become damaged or blocked.

How the food is given

- Continuous feeding via an electric pump: Feed is fed into the tube at a specified rate using a pump over a number of hours. It may be possible to do this overnight, leaving you free during the day. If required, some pumps can run on a battery and can be carried in a special backpack whilst being used for feeding. This can provide flexibility during the day
- Bolus Method: Feed is fed into the tube using a syringe. To meet your needs, a number of bolus feeds throughout the day will be required

Your Dietitian will advise on the most suitable way for you.

After PEG or RIG

A gastrostomy tube generally lasts for one to two years and can be replaced easily if necessary.
You may briefly experience a few, usually mild symptoms as your body adjusts to this new method of feeding:

- Redness on the abdomen around the tube entry site
- Regurgitation of feed
- Changes to bowel habits
- Increased saliva flow

These are usually temporary and your Dietitian and Public Health Nurse will be available to offer advice.

Some other symptoms associated with eating and drinking

Dry mouth (Xerostmia)

This can be caused by not enough to drink, which may be a sign of dehydration, or the side effects of some drugs which dry your mouth:

- If possible, increase amount of fluids, thickened if necessary. Sips of very cold water with ice cubes may help
- Fill a small spray bottle with water and keep it in the fridge or try mouth freshener spray
- Discuss with your GP – some medications can cause a dry mouth
- Wipe the mouth with lemon and glycerine swabs (available from your Public Health Nurse). For some people, sharp tastes such as lemon can cause coughing so use with caution at first
- Try squeezing a small piece of lemon under your tongue. This can increase saliva production
- Artificial saliva sprays may help, so contact your GP or Public Health Nurse for further advice
- Bioxtra products can provide relief from dry mouth. Gel products (versus sprays) can be useful if you are experiencing difficulty swallowing

Difficulty taking medication

- If you are having difficulty swallowing tablets, try taking them with yoghurt/ice-cream instead of water
- Some tablets are also available in liquid/patch/suppository form, check with your GP/Pharmacist
- Some drugs can be given through a gastrostomy tube
- While some medications can be crushed, others cannot (e.g. enteric-coated tablets, buccal & sublingual tablets, sustained-release & controlled release tablets, cystotoxics, hormonal & immunosuppressant tablets, or chewable tablets, e.g. Oxycontin). Check with your GP/Pharmacist

Drooling (Sialorrhea)

- Drooling indicates a weakness in swallowing as saliva becomes harder to manage
- Management depends on the type of saliva (i.e. if it is thick or thin)
- Management options include drinking natural products (e.g. sage, grapejuice) and using a supportive collar. Some medications can also be prescribed by your GP to reduce saliva production (e.g. Hyoscine patch, Atropine, Amitryptiline)
- In the minority of cases, radiation of the salivary glands or injection of botox into the salivary glands can be considered

Altered sense of taste

You may find your sense of taste alters or disappears altogether. Strong, spicy or acidic flavours may help but some people find that these make coughing worse. Taste may be affected by thrush or sticky saliva, which can coat the mouth.

Mouth care

It may become difficult to control the way food moves around your mouth and it can become stuck in the roof of the mouth, between the teeth and cheeks. In addition poor tongue movement and soft diet may cause you dental problems, and weight loss may loosen your dentures.

To keep your mouth clean, fresh and healthy:

- Ensure that all food has been cleared from the mouth at the end of a meal
- Swab the mouth with a cotton-bud soaked in a solution of bicarbonate of soda and water (half a teaspoon to a glass of water)
- Clean teeth thoroughly, at least twice a day. An electric or long, angle headed toothbrush may help. Use a small amount of low foaming toothpaste
- Check that you are using the right toothbrush to prevent damage to gums
- Have regular dental check ups. The dentist may visit you at home

➜ See ‘Everyday Activities’ section

Changes in bowel habits

MND does not affect the muscle in the gut or the sphincter muscle that controls bowel action. However, you may experience changes to your bowel habits because of:

- Changes in diet – not enough food, liquid or fibre
- Some types of medication, particularly for pain relief
- Reduced mobility
- Weakness of pelvic floor and abdominal muscles
- Adjusting to PEG feeds – can cause constipation or diarrhoea in the early stages

➜ See ‘Symptoms’ section

Some ways to help:

- Modify your diet by trying to include more foods containing fibre
- Make sure you get enough liquid
- Keep to a regular routine
- A physiotherapist can advise about assisted exercise
- Ask for advice from a Dietitian, your GP, Public Health Nurse or a Pharmacist

Regurgitation/Acid Reflux

You may have difficulties with food coming back up after you have eaten (known as regurgitation and/or acid reflux). This is generally due to weakness in the diaphragm (the large muscle involved in breathing), which normally forms a tight band around the stomach to keep food and acids down.

- Try to avoid foods that commonly cause reflux e.g. spicy foods
- Avoid eating late at night/lying down after meals
- Cut down on caffeine and try not to over eat as these can make the problem worse

Talk to your GP about medication that may help.

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