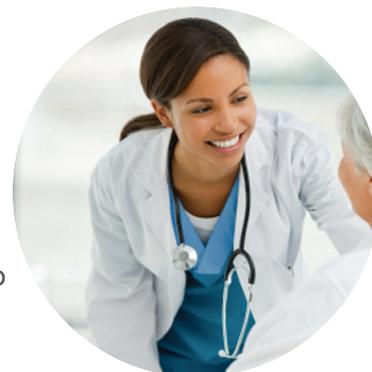


Symptoms

“People should receive explanation regarding any symptoms that have developed. It is important not to make any false promises but we can undertake to do everything possible to alleviate and minimise troublesome symptoms. Each new symptom as it develops needs careful analysis to establish a cause.”



Be aware that not every symptom you may have will be caused by MND.

There may be something else that needs attention. Symptoms may have a simple cause that can be easily treated so talk to your GP.

Equally, everybody has a different experience of MND so you may experience symptoms not listed here. Nobody should expect to put up with uncomfortable symptoms. Discuss them with your GP so they can be effectively treated.

The topics covered in this section are: other symptoms you may experience with MND and ways of coping with them.

Pain

Pain and discomfort are not caused directly by MND but may have several indirect causes:

Muscle cramps and spasms – often start as you relax in bed

- Relieve cramp by straightening and stretching the affected area
- Good posture in bed or in a chair can help spasms to occur less often
- Your doctor may prescribe Quinine or muscle relaxant medication
- The dosage and timing of muscle relaxants will need to be carefully adjusted to fit in with your daily activities. They can increase weakness, which reduces mobility

Jaw spasm – sometimes associated with yawning. Muscle relaxants can help

Stiff joints

- A Physiotherapist can teach exercises to do yourself or with the help of a carer to keep joints mobile
- Careful positioning when seated helps to relieve discomfort

Skin pressure

- Keep skin healthy with a nourishing diet → See 'Eating and Drinking' section for further information.
- Change your position regularly
- Special cushions and other equipment can be provided by the IMNDA by talking to your MND Nurse Specialist, Public Health Nurse or Occupational Therapist
- Pain relieving medication can help

Swelling

- Swelling, particularly in the ankles may be caused by restricted activity
- Try to keep your legs raised when seated

Watery Eyes

- Slackness in the muscles of the face may result in the normal lubrication of the eyes overflowing
They may feel sore or gritty
- Eye baths and drops may help – consult your MND Nurse Specialist or Public Health Nurse

Continence

- Incontinence of urine or an urgent desire to pass urine can occur with MND. This can be treated with medications. Problems may have other causes, perhaps linked to getting older. Accidents may happen when it takes more time to get to the toilet and remove clothing. Your OT can offer practical advice.

→ See 'Everyday Activities' section and 'Movement and Mobility' section for further information.

Bowel Problems

Regular bowel habits are important for health and well being. People's idea of normal bowel and bladder habits will vary, and changes in lifestyle like diet or exercise will make a difference.

MND does not directly affect the muscles involved in bowel movement but other changes caused by MND may have an effect, most likely constipation. These include:

- Restricted mobility, ask a physiotherapist for advice on assisted exercise
- Changes in diet, which are adopted in order to cope with swallowing problems, may reduce your intake of fibre and fluid. If possible, increase the fibre content of your diet. Do not be tempted to reduce your intake of liquid in order to cut down on trips to the toilet
- Dehydration

Constipation can also be a side effect of pain relieving medication so talk to your Doctor, MND Nurse Specialist or Public Health Nurse.

Diarrhoea is uncommon. It sometimes occurs during the period of adjustment to PEG feeds.

Ask for advice. → See 'Eating and Drinking' section for further information.

Excess Saliva & Mucus

We all produce up to two litres of saliva every day. It lubricates food, as it is chewed easing swallowing. It keeps the mouth moist and healthy.

If you have problems with swallowing, saliva and mucus can build up in the mouth and throat.

This is embarrassing if it results in 'dribbling' and naturally many people feel shy and rather ashamed of this.

The problem may be helped in a variety of ways and you should seek advice from your Neurologist, Speech & Language Therapist and /or Physiotherapist.

Watery saliva

• Posture

A well supported head position; such as a reclining chair, collar, chin support or headband.

Sleep on your side or in a reclined position rather than flat; this prevents saliva 'pooling' in the throat.

- **Swallow more frequently**

You may have to make a conscious effort to do this if the swallow reflex has been lost.

- **Medication**

Drugs can be prescribed to dry the mouth and reduce the amount of salivation. Discuss this with your Doctor - it is often a fine balance between too much saliva and too little causing a dry mouth but for many people it is worth considering.

- **Radiation**

A small dose of radiation to the salivary glands can be very effective and is used when medication is ineffective. This is organized through St. Lukes Hospital, Dublin, and can be arranged in discussion with your neurologist.

- **Suction pump**

This is rather like the one used by a dentist. A small tube attached to the pump is placed in the mouth and sucks out excess mucus /saliva. You or your carer can operate it.

Your GP or Public Health Nurse can provide a suction pump. Both stationary and portable battery operated pumps can be loaned from the IMNDA.

It is important that a Nurse or Physiotherapist assesses you first and demonstrates its use to you

- Clothing can be adapted to provide a discrete waterproof-backed insert
- Use barrier cream to protect the skin

→ See 'Everyday Activities' section for further information.

Thick, stringy saliva

This can be very distressing and may be caused by dehydration, breathing through the mouth causing evaporation, or the side effects of some drugs.

Diet can help. Here are some suggestions:

- Make sure you are getting enough fluid
- For some people dairy products such as milk and cheese seem to make the problem worse so you could try reducing these for a while to see if it helps
- Remember that these foods are a very good source of calories so make sure you balance your diet and make up for their loss. Ask a Dietitian for advice
- Try drinking apple, grapefruit, cranberry, dark grape and pineapple juices – these can help break down the protein in the mucus. They can be sipped or frozen into icy sticks

Coughing and choking

Coughing or choking is the body's way of getting rid of food or drink that is in danger of passing down the airway, instead of the oesophagus (gullet). The food or liquid may be lodged in crevices behind the soft palate (back of the roof of the mouth) and becomes sucked down when breathing occurs. Choking may not occur immediately, but a second or two after the introduction of the food. It can also happen spontaneously for no obvious reason.

Choking is one of the problems that people with MND fear most. It is frequently stated in the media and elsewhere as the main cause of death. **The truth is that though choking is relatively common it is almost never fatal.**

A Speech & Language Therapist or Physiotherapist can teach you and your carer techniques to help you manage these episodes:

- Prevention, with advice about 'safe swallow'
- Keeping calm and trying to relax

- How to retrieve whatever has caused the choking from the mouth
- The correct posture leaning forward with your head above your knees
- Haemlich's manoeuvre (rarely necessary)
- Medication to dry up secretions or relax muscles

Do not be tempted to slap the person on the back – it makes them breathe in, making the situation worse rather than better.

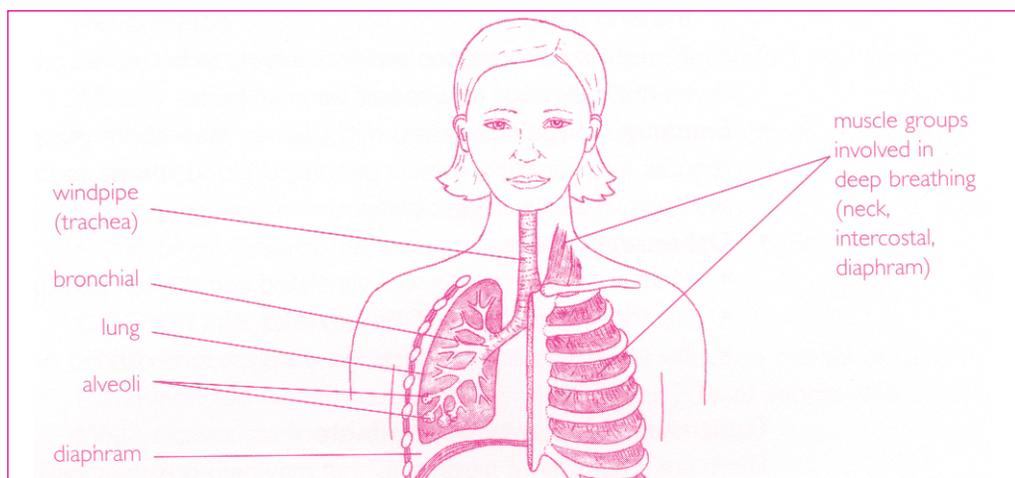
Breathing

Sooner or later MND weakens the muscles that control breathing. This section explains how this happens and what can be done to help.

Normal breathing

- Intercostal muscles between the ribs lift upwards and outwards and the diaphragm moves down when you breathe in
- This creates a partial vacuum in the chest cavity so air can be drawn into the lungs
- In the lungs oxygen from the air enters the bloodstream and waste is removed

Breathing is normally an involuntary activity but we can change the speed or depth of breaths. Sometimes we use our neck and shoulder muscles to assist.



What goes wrong with breathing

- Muscles between the ribs and the diaphragm weaken so breathing becomes shallow. Neck and shoulder muscles start to be used to assist
- Less air is drawn into the lungs so less oxygen is absorbed into the blood
- It is more difficult to get rid of carbon dioxide

What happens when things go wrong

• Shortness of breath

- You may not notice this if you are not very active
- You may get breathless when you talk
- Coughing may be more difficult
- The voice becomes quiet and faint

• Tiredness and fatigue

Shallow breathing can result in tiredness even though you don't notice being short of breath

- **Disturbed Sleep caused by shallow breathing can cause:**

- Nightmares, sweats, anxiety and panic attacks
- Waking up feeling tired, confused, 'hung over' and headachy
- A tendency to fall asleep during the day

What you can do to help

- **Exercise**

- A Physiotherapist can teach techniques to help with breathing.
The aim is to maximise lung capacity, muscle elasticity and to protect the lungs against infection

- **Posture**

- When seated, a well supported, slightly reclined position will give your chest maximum freedom to expand and contract
- Your back, neck and head should be well supported
- If breathing is laboured try leaning forward on hands or elbows when seated to create a supportive framework
- At mealtimes you need to be more upright to prevent food going down the wrong way
- At night a semi-reclined position is likely to be more comfortable
- A mattress elevator or a special bed can help

- **Smoking**

If you smoke you might like to think about giving up. Smoking reduces lung capacity, restricts peripheral blood vessels and reduces oxygen availability. It also increases phlegm.

- **Other suggestions**

- Make sure the room is well ventilated and the temperature comfortable
- Electric fans and humidifiers may help
- Try vaporisers and products like eucalyptus oil dabbed on a handkerchief

Machines that help with breathing: 'Non invasive positive pressure ventilation' (NIV)

- Uses a machine, which boosts your own breathing
- Works through a mask by pushing in extra air when you breathe in
- They can be quite small and powered by mains electricity or a large rechargeable battery
- They can be portable if attached to a wheelchair

Most people who use this equipment do so at night because breathing is shallower when you are asleep. Using NIV for more than 5 hours at night can improve both quality of life, and survival.

Invasive Mechanical Ventilation

This is performed in hospital. In Ireland, the use of full mechanical ventilation is uncommon, as there are no supports for home based care. People who undergo mechanical ventilation must remain in hospital, and are dependent for the remainder of their life. The use of full ventilation raises serious questions about quality of life.

Anxiety and Depression

It's natural to have a whole range of emotional reactions to your progressing disability. These are likely to affect you and those around you in different ways and at different times. Sometimes you may need help.

→ See 'Living with MND' section for further information.

Insomnia

Being unable to move around in bed often leads to discomfort may cause difficulty with getting off to sleep or wake you in the night.

- Electrically operated special beds will give you some ability to change your position
- Sleeping tablets are not recommended as they can interfere with breathing
- Sleeping problems may also be caused by anxiety and worries, so it is important to address these first

Cognitive Changes

Up to 50% of people who have MND experience some degree of difficulty in specific areas.

These are likely to be mild and may include:

- Poor concentration and forgetfulness
- Difficulties with word finding and spelling
- Difficulty with planning and organising
- Problems with new learning
- Impulsiveness and inappropriate social behaviour



They can complicate adapting to other methods of communication when speech is lost. MND may be the direct cause of these changes or they may be caused by other factors such as changes to routine, a more restricted lifestyle, or respiratory problems which reduce oxygen supply particularly during sleep.

Ways of coping

These problems are familiar to many people as they get older and so are the ways of dealing with them.

- Provide memory aids such as lists and diaries and labels
- Avoid distractions – focus on the task
- Split tasks up into simple steps
- Introduce variety into daily routines as cues to memory
- Give positive feedback

Dementia

In Ireland, MND is accompanied by a form of dementia in up to 15% of cases.

This is much more severe than the mild changes described above. Carers have described this change as “s/he is not the same person”.

Some particular changes, which may occur include:

- Socially undesirable, inappropriate behaviour
- Acting without thinking, inability to delay gratification
- Persists in activity not suitable to the situation
- Difficulty in initiating ideas, conversation
- May be withdrawn, apathetic and unable to initiate activities. This may be linked to depression

People with cognitive changes associated with MND should be reviewed at a specialist centre, with appropriate support from Neurologists, Neuropsychologists, Neuropsychiatrists and Specialist Nurses.

