

2: Managing symptoms

This section looks at the likely symptoms of MND, how these can be managed and who can help.

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**

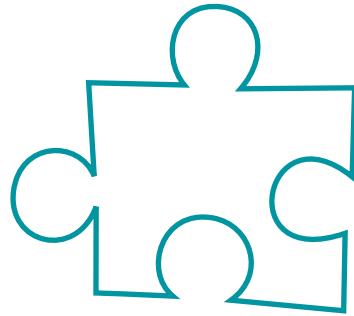
Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

2: Managing symptoms

This section looks at the likely symptoms of MND, how these can be managed and who can help.



What are the symptoms?

Not everyone will experience all of the likely symptoms, or in any particular order.

“ Things stay the same for several weeks, then one morning I find I can’t do something I could the day before.”

As the disease can affect everyone differently, you may have symptoms not mentioned here. You may also have an unrelated problem that needs medical attention. Ask your GP about any concerns.

The following looks at what is happening and what can be done for MND symptoms. Health and social care professionals are described later in this section.

See *Further information* at the end of this section for more resources.

Muscle weakness

What is happening? When motor neurones stop delivering instructions from the brain, the affected muscle is used less and reduces in mass (wasting). This causes weakness and can affect balance and posture, with risk of falls.

What can be done? Ask your GP or health and social care team for a referral to a physiotherapist or neuro physiotherapist. They can recommend an exercise programme to suit your needs, including assisted or passive exercise where someone moves your limbs for you.

A dietitian can also suggest ways to maintain weight, through changes to diet.

See Section 6: Getting around.

Exercise cannot reverse muscle wasting caused by MND, but it can support flexibility, range of movement, strength of unaffected muscles, posture and balance.

Twitching (and fasciculations)

What is happening? Twitching, and rippling sensations under the skin called fasciculations, are often early and annoying symptoms. Some people feel a rippling effect in individual muscles, but it can be widespread.

What can be done? Talk to your GP, neurologist or specialist nurse, as medication can help. This symptom usually fades over time.

Muscle tightness and/or cramping

What is happening? You may feel general muscle tightness (spasticity) as messages stop reaching your muscles. This can impact on mobility and co-ordination of movement, which may cause pain or increase the risk of falls. Sudden muscle cramps or spasms are also common and can be very painful.

“ For me, relaxation is the answer to sudden stiffness or spasm. I’m getting better at relaxing, but over time, more things cause stiffness to happen.”

What can be done? Ask your health and social care team about physiotherapy or medication that may provide some relief. They can also advise you and your carers on managing falls. Appropriate positioning when sitting or lying down can help you feel more comfortable.

Breathing problems

What is happening? Problems with breathing may develop, often in the later stages of the illness. The internal respiratory process is not affected, but the muscles involved in the control of breathing can weaken.

What can be done? If you have shortness of breath, fatigue, disturbed sleep, morning headaches or daytime sleepiness, you may be referred to a respiratory consultant for assessment. Depending on your needs and preferences, assistance can include breathing exercises, physiotherapy, advice on careful positioning, guidance on effective coughing, medication and assisted ventilation (where a machine provides breathing support). There are two types of ventilation:

- non-invasive ventilation (NIV), where a machine supports your breathing by providing extra air through a mask
- tracheostomy ventilation (also known as invasive ventilation), where a machine supports your breathing by a tube, which is inserted into the windpipe through an opening made in the neck.

NIV has traditionally been more common with MND, but ask about both types of ventilation at your breathing assessment. It's important to find out what's available in your area, and the support needed if you decide to go ahead with either type of ventilation.

“ Despite general caution about tracheostomy ventilation, I decided to proceed after deliberations with my family and extensive reading of research papers.”

You may only need assisted ventilation for short periods at first, or overnight. As your breathing muscles continue to weaken, you are likely to become dependent on it if you continue to increase its use. It can help to ease breathing difficulties and prolong survival, but your symptoms and care needs will continue to progress. Being fully informed about ventilation options, benefits and risks, can help you make decisions that feel right for you and your future care.

You may decide not to increase use of ventilation as your muscles get weaker. If so, you can use medications to help with the feeling of breathlessness. The medications can't make your breathing muscles work better, but they do help to make breathing more comfortable. Ask your health care team if you want to know more, and if you wish to stop using ventilation at any stage of your illness. We have information to help.

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

“ I found wearing an NIV mask not as claustrophobic as expected. I practised for a short time each day for a couple of weeks. Then wearing it all night was easy.”

Oxygen: is not usually recommended as a treatment with MND, as it can upset the balance between oxygen and carbon dioxide in your body. However, controlled use in small amounts may be used if your oxygen levels are low. In most cases, assisted ventilation uses normal air to help you breathe, not oxygen.

Our alert wristband lets hospital staff know you have MND and may be at risk with oxygen, as they may not be aware of the need for caution, especially with higher doses. It is your choice whether to wear the wristband or not, but it may help if you need emergency treatment and are unable to communicate for any reason. The wristband is included in the folder with this guide or can be ordered from our MND Connect Helpline.

See Further information at the end of this section for contact details.

Swallowing problems

What is happening? If your face, mouth and throat weaken (due to MND affecting your bulbar muscles), you may have problems with swallowing. Difficulty with swallowing is called dysphagia, and may mean you don't eat or drink as much as you need. You can lose weight from this and from muscle wasting.

What can be done? Discuss any issues with your health and social care team and ask to be referred to a speech and language therapist (SLT) and a dietitian. An SLT will assess your ability to swallow and advise on consistencies of food and drink. They can also provide guidance on how to manage coughing and choking if you experience these when eating and drinking. A dietitian will assess your weight and advise on whether to increase calorie intake. This can be helped with changes to diet, but also with supplements if needed. In time, if your swallowing difficulty gets worse, tube feeding can top up or replace meals.

See Section 9: Eating and drinking.

Tube feeding is a way of passing fluids and specially prepared liquid feed straight into your stomach, through a tube in your abdomen. This requires an operation in hospital, but the tube is easy to use once fitted.

Saliva and mucus problems

What is happening? If your swallowing is affected, saliva can gather in the mouth and throat, and lead to drooling, which many people find embarrassing. Saliva may be watery, or thick and sticky. If your mouth is dry, mucus secretions can thicken, which can be difficult to clear if your cough weakens. Dryness of the mouth can result from medication, thrush, dehydration or breathing through the mouth.

What can be done? Talk to your health care team as various options can be offered, depending on the circumstances. These can include advice on diet and fluid intake, the use of medication and occasionally suction machines for clearing out the mouth.

Speech and communication difficulties

What is happening? If muscles in the lower face and throat weaken (bulbar muscles), the way you speak and sound can be affected. This gets worse over time. Weakened breathing can also affect volume. Difficult or unclear speech is often referred to as dysarthria. Muscle weakness in your face, arms and hands can also affect gesture and expression.

“ I try to make people aware that I need time to communicate, otherwise I feel left out of conversations.”

What can be done? A speech and language therapist (SLT) can assess your communication needs, and suggest techniques and suitable communication aids. An occupational therapist (OT) can assess your physical needs for equipment or aids around the home. Speech and communication aids are often referred to as Augmentative and Alternative Communication (AAC).

AAC can range from low tech (gestures, notepads, alphabet boards, etc) to high tech (computer based). Voice and message banking can also help to preserve the sound of your own voice, for use with computer based communication aids.

See Section 8: Speech and communication for further details.

Fatigue

What is happening? Loss of physical function means that everyday routines take longer and become more tiring. Fatigue can also occur from breathing problems, breathlessness, low calorie intake and not drinking enough.

What can be done? Be flexible with daily routines to make the most of when you feel alert and then allow for rest. An occupational therapist (OT) can advise on fatigue management and aids to make daily tasks easier. A dietitian can advise you on calorie and fluid intake to maintain energy. A speech and language therapist can advise on swallowing techniques and consistencies of food and drink.

Pain

What is happening? Pain may be experienced due to muscle cramps, stiff muscles and joints, muscle spasms, skin pressure or constipation. You may also experience discomfort from fluid retention or swelling, caused by limited mobility (known as oedema). Some people experience intense itching.

What can be done? Always ask your GP or another health professional about any discomfort, pain or itching. It may not be connected to MND and needs checking. Something can usually be done to ease these symptoms. Ask your health and social care team for advice on careful positioning, support, pressure care and medication. If you have fluid retention or swelling, you may be referred to the lymphodema service. If pain is persistent, ask for referral to a specialist palliative care team or pain clinic.

Emotional lability (also known as pseudobulbar affect)

What is happening? You may experience inappropriate laughing, crying or outbursts that are difficult to control and feel distressing. This does not affect everyone with MND and is an involuntary response.

What can be done? Talk to your health and social care team who can support. Medication may help. This can be alarming for those close to you or providing support, but once recognised as an MND symptom, it can be easier to manage.

See Section 4: Emotional impact for more on emotional lability.

Emotional reactions

What is happening? You may feel you are on an emotional roller coaster, experiencing multiple emotions, such as anxiety, fear, anger, sadness, depression and disbelief. These reactions are common and to be expected.

What can be done? Trying to understand what you are feeling can be the first step towards managing these emotions. If they are persistent and extreme, ask your health and social care team for support. You may need referral to an appropriate counsellor or psychologist. There is often a waiting list for this type of service, but there may be alternative services through specialist palliative care teams and hospice care. Medication may also be helpful.

See Section 4: Emotional impact.

Changes to thinking and behaviour

What is happening? You may find it harder to think, concentrate, interact and plan as easily as you used to. These changes to thinking and behaviour are known as cognitive change. Those close to you may notice the changes before you do.

Up to half of people with MND are thought to be affected, with mild effects in most cases. This number can increase in the later stages of MND. A few people experience more noticeable change and a very small percentage develop a type of dementia called frontotemporal dementia (FTD), which is more severe.

What can be done? Additional support is likely to be needed, including mental health and psychological services. If you or your carer have any concerns, ask your neurologist about the possibility of screening. This assessment process can help detect changes to thinking and behaviour, so that appropriate support can be arranged.

What is not affected by MND?

The following are usually unaffected, although each individual has a different experience. Talk to your GP or health and social care team if you have any concerns, as there may be an underlying condition.

Taste, sight, smell, touch and hearing

Senses are generally unaffected, but some people experience changes to taste, skin hypersensitivity or problems with temperature regulation. MND symptoms can also impact on your senses, such as muscle tightness causing pain.

Continence

Your bowel and bladder are not usually affected, but some people do report a sense of urgency to pee with MND. Getting to the toilet and using facilities may be harder if mobility is affected. Constipation may happen with changes to eating, dehydration, anxiety, medication or poor mobility. Persistent constipation may lead to diarrhoea. Discuss any changes with your health professionals. They can help and problems may not be due to MND.

Sexual function and expression

Sexual function is not usually affected, but MND will make movement and expression more difficult. Your sense of identity and sexual desire can also change. Physical changes can affect intimacy at all levels, from cuddling to having sex. Open discussion with your partner, and your health and social care team, can help you find ways to maintain intimacy.

Eye muscles (and head support)

Most people with MND retain the ability to move their eyes. If you do experience any changes, discuss these with your health and social care team to help work out the cause. Being able to use your eyes also depends on positioning of your head, which may be affected by weakness in your neck muscles. Appropriate head supports can help.

Who can help?

With MND, much can be done to help you manage symptoms, adjust to the emotional impact and maintain independence, for as long as possible.

Ask your GP for general advice on symptom management and medication, and for referral to other specialists. Other health and social care professionals can also make referrals.

In most areas, you can now access your GP records online. This can help you keep track and some surgeries allow you to book appointments online too.

Ask for information at appointments, when needed. If you are disabled and need information in a particular format, this should be provided by the health or social care service you are dealing with. This is now mandatory in England - for more details, search for *Accessible Information Standard* at: www.england.nhs.uk

“ Questions to ask the professionals are really useful when making decisions. Have some valid questions ready for appointments.”

The multidisciplinary team

With MND, you are likely to meet a wide range of health and social care professionals. As MND is not common, many have no experience of supporting people with this disease. They are more likely to have relevant expertise if they work through an MND care centre or network, or your local neurological service. You are likely to have access to a multidisciplinary team (MDT) through these clinics. This is where professionals work together to provide co-ordinated care and linked services, including some or all of the following:

Neurologist: a consultant who specialises in the brain and nervous system, for assessment, diagnosis, symptom management and advice on care management.

Consultant: depending on your symptoms, you may be referred to other consultants who may specialise in areas such as respiratory medicine or palliative care.

Neurology or MND specialist nurse: for specialist advice and information about neurological conditions such as MND. However, this role is not always available in every region.

MND care co-ordinator: sometimes a specialist nurse or other discipline, such as an occupational therapist or physiotherapist, who provides assistance at an MND care centre or network. They act as a link between you, the multidisciplinary team, community services and the MND Association. A similar role is sometimes available through local neurological services.

Community or district nurse: for help with medication, monitoring of symptoms, skin pressure, provision of home nursing equipment and advice on local services. A community or district nurse works closely with your GP and can make home visits if needed.

Specialist palliative care services: including symptom management, counselling, emotional and spiritual support, complementary therapies, practical guidance, support groups and information resources. You may receive this support as an outpatient or through home visits. Short stay admissions may sometimes be needed for assessment or support, often in a hospice setting. Palliative and hospice care is designed to help you achieve the best possible quality of life throughout a life-shortening illness. Once you have been referred, these services are available for your family and main carers too.

“ Get all the help you can. Your local branch of the MND Association is a good start...and don’t be afraid to contact your local hospice, as their services can help at every stage of MND.”

Wheelchair services: for assessment of seating needs and provision, as appropriate. Please be aware that there are often waiting lists.

Occupational therapist (OT): for advice on posture, equipment and home adaptation, to help you continue daily routines with as much independence as possible.

Physiotherapist: for guidance on managing symptoms, such as cramps and stiffness. They can advise on positioning and appropriate exercise, including assisted exercise. While exercise cannot delay the progression of the disease, it may help maximise use of unaffected muscles and increase your flexibility.

Speech and language therapists (SLT): for assessment and help with speech and swallowing difficulties. Assessment is recommended before purchasing any communication aids, as these can be expensive and not all solutions suit everyone. An SLT often works closely with a dietitian for swallowing difficulties.

Dietitian: for help with nutrition, maintaining a healthy weight and guidance about tube feeding.

Pharmacist: for advice on the best types of medication in particular circumstances. For example, many drugs can be dispensed as a liquid for ease of swallowing.

Counselling and psychology services: for emotional and psychological support. Your GP can usually refer you to an appropriate service, counsellor or psychologist, but there may be a waiting list. Hospices and specialist palliative care teams usually offer counselling as part of their support.

Complementary therapist: for therapies that may help ease symptoms and reduce anxiety, such as massage, reflexology or acupuncture. These therapies cannot reverse the progress of MND. Rather than replacing conventional medicine, they work alongside it. Contact your GP before any complementary therapy, to check it will not conflict with current treatment, and ask to be referred to a registered practitioner. Many hospices also offer selected complementary therapies as part of their service and may include this service for carers too.

“ My physiotherapist suggested acupuncture to relieve stiffness in my neck. I was sceptical at first but it made an amazing difference.”

Social worker or care manager: for assessment of your daily needs and those of your carer. These professionals work for adult social care services or other related local services. They can provide information about local care services and support.

Benefits adviser: for help with benefit claims and enquiries. They may seek medical evidence from your health and social care team to support a claim. You can also search for government online information about benefits at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

See Section 12: How we can help you for details about our services through the MND Association.

Are there any medications for MND?

Depending on your symptoms, various types of medication may be prescribed to help. At first sign of a developing symptom, ask your GP first. You will be referred to a specialist if necessary.

Riluzole

Only one drug is currently licensed and approved for use with MND in the UK, called riluzole. It's available through the NHS under more than one brand name. It can be taken as tablets or a liquid and is the first medicine to show a modest impact on survival with MND, of a few months.

Ask your neurologist for assessment and details about riluzole, but your GP is likely to be the prescribing doctor. If you have any problems in obtaining this drug, let our MND Connect helpline know.

See Further information at the end of this section for contact details.

New medications

Researchers continue to investigate other drugs to help people living with MND. Several clinical trials are underway, where people meet the qualifying criteria. We have a research list to register those who might be interested in taking part in future trials: www.mndassociation.org/researchlist
Telephone: 01604 611880
Email: research@mndassociation.org

Making a complaint

If you feel that you're not receiving appropriate treatment or social care support, you have the right to complain. Try to discuss your concerns first with the service involved, as this may solve the problem. If not, you can take the matter further and there are organisations that help patients with queries and complaints.

See *Further information at the end of this section for details about patient councils that can assist with complaints. See Section 13: Useful organisations for more contacts.*

The NICE guideline on MND (from the National Institute for Health and Care Excellence) gives recommendations for the treatment and care of MND. This is not a legal document, but health and social care professionals are encouraged to follow these guidelines. This may support you when making a complaint - see our information sheet 1A: *NICE guideline on motor neurone disease*.

See *Further information at the end of this section.*

Key points

- Not everyone gets the same symptoms in the same order, or at the same speed.
- Not all health and social care professionals are familiar with MND and may not be aware of every symptom. Ask for referrals as soon as you develop symptoms that require specialist help.
- Ask for a referral to a hospice or specialist palliative care team as soon as possible after diagnosis. There is much they can do to improve your quality of life. Their detailed knowledge of your case may also help you spend less time in hospital, if a stay is needed.
- If planning to buy equipment or aids, ask for an assessment of your needs by an occupational therapist to avoid unnecessary expense.
- If you have any difficulties with the supply of riluzole, please contact MND Connect, as shown next in *Further information*.

Further information:

From our range of information sheets:

- 1A: *NICE guideline on motor neurone disease*
- 1B: *How to get health information in other languages or formats*
- 2B: *Kennedy's disease*
- 5A: *Riluzole*
- 6A: *Physiotherapy*
- 6B: *Complementary therapies*
- 6C: *Managing pain*
- 7A: *Swallowing difficulties*
- 7B: *Tube feeding*
- 7C: *Speech and communication support*
- 7D: *Voice banking*
- 8A: *Support for breathing problems*
- 8B: *Ventilation for motor neurone disease*
- 9A to 9C:
our range of sheets on thinking and emotions in MND
- 11C: *Equipment and wheelchairs*
- 11D: *Managing fatigue*
- 13A: *Sex and relationships for people living with MND*
- 13B: *Sex and relationships for partners of people living with MND*

From our guides and other publications:

MND Checklist: a questionnaire that helps you think about your condition and how to plan and prepare for your care needs.

Understanding my needs: a booklet in which you record your needs and preferences to guide all those involved in your care.

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

Caring and MND: support for you: a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide: a booklet to help someone new to the caring role.

Information to pass to your health or social care professionals:

- P1: *Head supports*
- P3: *Managing saliva*
- P6: *Evaluation and management of respiratory symptoms*
- P8: *Managing dysphagia in motor neurone disease*
- P10: *Voice banking*
- P11: *Pain in MND*
- Caring for a person with MND – a guide for care workers*
- Cognitive change, frontotemporal dementia and MND*
- Occupational therapy for motor neurone disease*
- Motor neurone disease – a guide for GPs and primary care workers*
- Multidisciplinary team working for 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 development adviser (RCDA).

See Section 12: How we can help you.

MND Association Support Services:

For guidance on our MND support grants and equipment loan services:

Telephone: **0808 802 6262**

Email:

support.services@mndassociation.org

Online forum:

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

<http://forum.mndassociation.org>

Health and social care in Northern Ireland:

Online information about health and social care services in Northern Ireland at

www.hscni.net

Health in Wales:

Online information about NHS services in

Wales at **www.wales.nhs.uk**

Health Professions Council (HPC):

A register of qualified health professionals at

www.hpc-uk.org

Telephone: **0300 500 6184**

NHS information:

Health information and NHS services.

www.nhs.uk

NHS 111:

NHS 24-hour help, for urgent, but non-emergency medical advice. **www.nhs.uk**

or contact Helpline: **111**

NHS Direct Wales:

Similar to NHS Direct, but particular to Wales.

www.nhsdirect.wales.nhs.uk

Telephone: **0845 46 47**

Local authorities or health and social care trusts:

Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland, about adult social care services, needs assessment and complaints on social care.

Confidential advice and making a complaint about healthcare::

England:

Contact the Patient Advice and Liaison Service (PALS). Search for PALS on the NHS website: **www.nhs.uk**

Northern Ireland:

See the Patient and Client Council at:

www.patientclientcouncil.hscni.net

Wales:

Find your local Community Health Council.

www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils

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For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

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



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