MND Association | For professionals

MND: a guide for GPs and primary care workers

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About Motor Neurone Disease

This publication is designed to provide information for GPs caring for someone with MND. In this fold-out page, you'll find key information on the effects of MND and a typical journey of a person with MND.

If you'd like to learn more about a topic, click on the relevant heading, or use the tabs on the side, to be directed to the corresponding section within the guide. You'll find in-depth guidance on symptom management, your role in care, and referrals to specialist support.

Download our Red Flags Tool to see the early signs of MND. If MND is suspected, refer the person for an urgent review to a neurologist, specifying the possible diagnosis: **mndassociation.org/redflag**

MND is a fatal, rapidly progressing disease.

It affects the motor neurones in the brain and spinal cord, causing the dysfunction of voluntary muscles.

Symptoms typically appear between ages 54-67, but this may vary.

Symptoms progress at different speeds and a different order for everyone.

Symptoms typically start in one area, such as the hand or foot.

In a third of people, they first develop in the face and mouth. Rarely, they first affect respiratory muscles.

More than half of people will die within two years from the diagnosis.

The most common cause of death is respiratory failure. Death from choking is very rare.

There is no cure, but symptom management can improve quality of life.

Co-ordinated multidisciplinary care and anticipating care needs are key.

People can experience cognitive and behavioural changes.

Some may develop frontotemporal dementia. In some cases, these are the presenting symptoms.

A case study of a typical journey with MND

Adam, 59, first presented to his GP after his partner noticed muscle fasciculations in his leg. While fasciculations can be benign, Adam also described increasing difficulty when climbing stairs, slower walking, and more frequent trips and falls, sometimes catching his right foot. He also reported that friends had recently commented on his slurred speech and asked whether he had been drinking. Adam had attributed these issues to ageing and tiredness.

On examination, the GP noted muscle wasting in the right foot. The combination of progressive motor symptoms, fasciculations, and absence of sensory loss raised concern about a neurological cause, **prompting an urgent referral to neurology**. Following speciailist assessment, the neurologist told Adam that he had MND, and proposed starting riluzole, the only UK-licensed disease-modifying drug for MND. The neurologist informed the GP of the confirmed diagnosis and they **worked together to arrange ongoing prescriptions** and **introduce Adam to the local MND Care Centre** and multidisciplinary MND care team.

Over the following months, Adam's mobility, speech and swallowing worsened, and he was supported by the MND team. He later presented to his GP with morning headaches and poor sleep. Recognising these as possible signs of respiratory insufficiency, the GP **referred him promptly** to the respiratory specialist. Adam also reported painful cramps and anxiety about how his family would cope as his condition progressed. The GP provided **symptom management**, suggested **referral to palliative care**, and **began discussions about advance care planning**, ensuring Adam's **decisions were documented and shared** with the MND team and the out-of-hours and emergency services.

In his final months, Adam's breathing deteriorated and he became fully dependent on non-invasive ventilation. Recognising that he was approaching end of life, the GP **coordinated care** with community, palliative, and MND teams to **ensure it aligned with his wishes**. Despite increasing communication difficulties, the GP **continued discussions with Adam and his family about their needs**, **arranging support** to maintain comfort and dignity, including communication aids, anticipatory medications and nursing support.

The effects of MND

The role of the GP: Your role includes providing prompt referrals from symptom onset throughout the disease, assisting with **symptom management**, introducing **palliative care** and **advance care planning** and supporting **end of life care** and **bereavement care**.

Mobility: MND causes muscles in the arms, legs, neck and torso to waste and weaken. This can cause **posture** and **balance issues**, and falls. It also causes problems with **movement** and **everyday activities**, such as walking, showering and cooking. People might need wheelchairs, support with personal care, home adaptations and assistive equipment such as orthoses and environmental controls.

Muscle problems: People often experience muscle **cramps**, **spasms** and twitching (**fasciculations**) which may be painful. These can be experienced in any muscles, including tongue and throat (laryngospasms). People can also experience other types of **pain** at any point of the disease.

Speech and swallowing: Weakness in the bulbar muscles in the face, mouth, tongue and throat lead to slurred, effortful speech or speech loss **(dysarthria)**, resulting in many people using communication aids. It also makes it hard to swallow food and drinks **(dysphagia)**, increasing the risk of weight loss, malnutrition and dehydration, choking and aspiration. People may use tube feeding, such as gastrostomy.

Medications: Dysphagia complicates swallowing. Advise on alternative forms of medications (like syrups) and their tube-feeding suitability. **Riluzole** is the only UK-licensed drug for MND. It modestly extends survival rather than stopping the disease, and comes in multiple formats. GPs and neurologists should agree a shared-care protocol with clear prescribing and monitoring roles.

Secretions: Difficulties include swallowing **thin saliva**, leading to drooling, clearing **thick saliva** or mucous secretions, and **dry mouth**.

Weak cough: Respiratory muscle weakness causes weak cough, which can make it harder to clear aspirated food/drinks/saliva, **increasing the risk of chest infections**.

Breathing: Weakness in the respiratory muscles leads to **breathlessness** on exertion or when lying down, and **respiratory insufficiency**. Some people may use assisted ventilation, such as non-invasive ventilation (NIV). **Oxygen therapy should only be used with great caution in people with MND-related respiratory problems, and under guidance of the specialist team.**

Non-motor symptoms: They may include cognitive and behavioural changes, fatigue, pain, secretion problems, constipation, urinary urgency and emotional lability.

Emotional needs: MND has a significant psychological impact on the person with MND, their carer and family. It's essential to provide **mental health support** and **assess the needs of the whole family**, including children, carers and young carers. Their roles as carers should be recorded on their own GP record and that of the person with MND, so they can have targeted support, including respite care.

Early palliative care: Reassure that referrals to palliative care do not mean that death is imminent. Add the person with MND to your **local palliative care register**, explain the benefits of palliative care services such as day care from diagnosis, and help the person access **fast-tracked financial benefits** under Special Rules for End of Life.

Advance care planning (ACP): Offer ACP discussions at diagnosis and throughout the disease, covering **future care, preferred place of death, ADRTs, DNACPRs, and Lasting Power of Attorney**. Document, regularly review, and share decisions with the care, emergency, and out-of-hours teams. Take into account the person's communication abilities, cognitive status and mental capacity, and consider discussing ACP earlier if these get worse.

End of life care: **Clearly communicate** when the person is near end of life. Although communication may be challenging, continue to **explore the wishes and needs of the person, their family and carers** (including spiritual beliefs and needs after death), so that care is delivered in line with these. **Establish early any resources needed**, including equipment, anticipatory medications, and external support to reduce the family's caring tasks.

Introduction

This booklet is divided into three sections.

Section 1: Recognising MND introduces this condition and the role you play in supporting its timely diagnosis and management.

Section 2: Managing MND symptoms includes an overview of motor and non-motor MND symptoms and how they can be managed.

Section 3: Palliative and end of life care highlights how palliative care can be provided from diagnosis through to the end of life. It also covers advance care planning and supporting benefit claims.

Helpful resources

NICE Guideline on MND: The National Institute for Health and Care Excellence (NICE) Guideline "NG42 — Motor neurone disease: assessment and management" aims to improve care from point of diagnosis through to end of life. **nice.org.uk/guidance/ng42**

We also produce infographics which summarise the NICE guideline NG42 recommendations. See page XX.

RCGP online module on MND: Visit **mndassociation.org/gp** to access the online module and other tools and information for GPs.

Publications for you and the people in your care: We have an extensive range of resources to help you understand and manage specific MND symptoms. You can search our information by topic or profession on **mndassociation.org.pro-info-finder**

We also produce resources for people with MND, their carers and family, including children and young people. Remember to share this information sensitively. **mndassociation.org/publications**

See page XX to learn more the MND Association support for you and people affected by MND.

1

Recognising MND

What is MND?

MND is characterised by the progressive degeneration of upper motor neurones (UMN) and lower motor neurones (LMN) in the brain, brainstem and spinal cord. This results in dysfunction of voluntary muscles in the bulbar (face, tongue and throat), cervical (neck), thoracic (chest), and/or lumbar (arms and legs) segments.[1,2]

Mobility, speech, swallowing and breathing can be affected, leading to loss of function and autonomy and increasing care needs. People with this condition require support from a team of multidisciplinary professionals. MND also significantly impacts families and carers.[3–5]

Amyotrophic lateral sclerosis (ALS) and MND essentially mean the same thing. MND is the overarching term, largely used in the UK and Australia. It is also sometimes referred to as Lou Gehrig's disease.

Causes and frequency: MND is thought to be caused by a combination of genetic, ageing and environmental factors. Inherited, or familial, MND accounts for about 10–15% of all cases. However, genetic factors have also been found to contribute to non-inherited MND, known as sporadic MND.[6]

There is a 1 in 300 risk of being diagnosed with MND. Men are slightly more often affected than women. About two people in every 100,000 of the general population will develop MND each year. However, because progression can be rapid, fewer people are living with the disease at any one time than you might expect.[2,7]

There is a wide variation in the age of onset. Typically, this occurs in late adulthood, between ages 54–67.[1] Juvenile (before 25 years old) and young-onset (before 45 years old) MND cases represent, respectively, about 1% and 10% of all cases.[1]

Progression: It can be rapid, and death usually occurs two to four years after the onset of symptoms, due to respiratory failure.[1,2,8] Not all symptoms affect everyone, and it is unlikely they will all develop at the same time or in any specific order. There is no cure for MND, but symptoms can be managed to improve quality of life. Effective, holistic care and anticipating care needs are central.[3,5,9]

Symptoms: LMN degeneration causes muscle weakness, atrophy, cramps, stiffness and fasciculations. Signs of UMN degeneration include slowing of movements, spasticity and hyperreflexia.[6]

Symptoms usually appear in one area and then spread to nearby regions along connected nerve pathways, without sensory changes. In most people, symptoms begin in an area far from the centre of the body, on one side, such as the hand or foot (limb MND). In a third of people, they begin in the bulbar area, affecting speech and swallowing (bulbar MND). Eventually, the majority of people with MND develop speech and swallowing difficulties, regardless of the site of onset.[6]

Depending on the areas affected, first symptoms can include:[1,2,6,10]

- weakness and functional effects of muscle weakness – foot drop, falls, difficulties climbing the stairs, weakened grip and loss of dexterity (for example, issues do up buttons or holding items)
- slurred speech
- tongue fasciculations and difficulties moving the tongue or closing the mouth
- muscle problems such as cramps, stiffness, wasting and feeling the limbs heavy. Muscle twitching (fasciculations) are also common. However, fasciculation can also happen with tiredness, stress, viral infection or general ill health. They are not usually associated with neurological conditions unless other symptoms are present.

Usually, weakness of the trunk and head muscles occurs later in the disease, causing posture issues and head drop. Respiratory muscle weakness is also likely to develop later. However, it can also be the presenting symptom, causing shortness of breath on exertion or when lying down, and signs such as daytime sleepiness, fatigue and early-morning headaches (respiratory onset MND).[2,6,10]

MND is now understood as a multi-system condition, with non-motor symptoms, too (see page XX). These can include:[4,11]

- cognitive and/or behavioural changes and frontotemporal dementia — these can also be the presenting features of MND and may mask motor symptoms
- pain
- fatigue
- secretion issues, including dry mouth, problems clearing thick saliva or mucus and excessive drooling
- emotional lability, anxiety and depression
- sleep problems and insomnia
- constipation and urinary urgency.

There is a significant variability in how MND symptoms can present and progress. This has led to the definition of various “types” of MND, which were historically classified by the body region first affected and the degree of involvement of UMN and LMN. For example, some forms of MND with predominantly LMN degeneration tend to have a slower progression.[1,6]

We have reported these types in the table on the next pages, as some people may have been given them as diagnoses. However, it is now recommended to view MND as a single disease with different presentations.

MND type	Onset and features[2,6,12–15]
Limb onset MND	— UMN + LMN — Symptoms start far from the centre of the body, on one side, such as the hand or foot. — It affects about two third of all people with MND.
Bulbar onset MND	— UMN + LMN — Symptoms begin in the bulbar region. — It affects about a third of all people with MND. — Shorter survival
Respiratory onset MND	— UMN + LMN — Affect about 3% of people with MND. — Shorter survival.
Flail arm syndrome	— LMNs are predominantly affected, with muscle weakness typically beginning in the proximal upper limb muscles (such as in the shoulder). — Weakness slowly progress in a symmetrical pattern. — Mild UMN dysfunction can occur in the legs.
Progressive muscular atrophy (PMA)	— LMN — Symptoms onset is generally later than typical MND. — Characterised by marked muscle wasting and weakness. — Symptoms can begin in any region.

Primary lateral sclerosis (PLS)	— UMN — Signs include spasticity, slowed movements and impaired balance. — Symptoms usually begin in the legs and progress to the arms and bulbar muscles. In some cases, they begin in the bulbar region. — Progression is slower than in typical MND. Survival can be longer than 20 years and gastrostomy is rarely needed even in those with significant swallowing issues. — Age of onset is earlier than typical MND, at around 50 years old.
Progressive bulbar palsy (PBP)	— LMN — Symptoms begin in the bulbar region, with rapidly progressive speech and swallowing problems, often accompanied by emotional lability (see page XX). — Symptoms may remain relatively confined to the bulbar region for several months (occasionally years) before progressing to the limbs. — It typically affects older women.

The role of the GP

People with MND have multiple, evolving needs that require holistic, multidisciplinary care (see page XX).[10] As a GP, you are often the first point of contact when medical issues arise, supporting symptom management and acting as a gatekeeper to specialist and community services.

You are also likely to have known the person and their family for longer than other professionals, giving you an understanding of their life, values and preferences before diagnosis. For these reasons, you can play a pivotal role in supporting quality of life and facilitating access to co-ordinated, person-centred care.

Your role includes:[5]

- prompting referral to a neurologist to investigate and confirm a diagnosis of MND
- linking the person and their family to the local MND care centre or network, and signposting them to relevant support services
- working with the MND specialist team, including agreeing on a shared-care approach with the neurologist.
- where an MND co-ordinator is not in place, the GP should support care co ordination by liaising with the other professionals, acting as a point of contact for the person and their family, and attending multidisciplinary team (MDT) meetings
- assisting with symptom management, including prescribing medications, managing pain, respiratory secretions and co-morbidities, and making timely referrals for specialist support
- introducing palliative care early and helping with advance care planning
- assisting with end-of-life care and offering bereavement support. Be aware that many people with and affected by MND experience anticipatory grief and requires ongoing support.

Quick actions for GPs and the primary care team

Information
Is the person correctly coded on your practice IT system so that their neurological condition is flagged when they contact the surgery?
Has the person been linked to the MND care centre or network? Find your nearest centre: **mndassociation.org/carecentres**
Has someone been nominated care co-ordinator?
Have you put the person’s name on your practice’ Supportive Care Register and informed the district or community nurse that there’s a person with MND in their area?
Have you notified your out-of-hours service provider that this person has MND? Ensure that they have access to relevant facts and wishes, too.

Care needs and household support
Have you recorded the contact details of the main carer? Flag them as a carer in your system and refer them for a carer’s needs assessment.
If the carer is registered with your practice, is their record cross-referenced on your system?
If there are any children in the household, have you referred the family to an early help assessment (EHA) and a young carer’s needs assessment?
Does the person need additional support for their personal care? Arrange for external support through social care services.
Are plans in place for emergency care provision if the person’s carer cannot support for any reason?

Treatment
If the person is taking riluzole, have you agreed on a shared care protocol with their neurologist to provide repeat prescriptions?
Are efforts being made to control all symptoms currently experienced? Use the sections of this booklet to learn more.
Palliative care, advance care planning and end of life care
Is the person registered on your palliative care register?
Do you know the person's wishes in relation to end of life?
Have end of life wishes been recorded and shared with the care team? Encourage the person to record their wishes and make their family, carers and clinicians aware. They should also always keep a record in a known place that is easily accessible.
Do you have a copy of any existing DNACPR order/ ADRT/ advance care plan/ preferred place of care request in your practice records?
Is the ambulance service aware of any DNACPR order/ADRT/ preferred place of care request?
Is the person eligible for benefits under the Special Rules for End of Life and aware of the benefits they may be entitled to?

Supporting diagnosis

An early diagnosis is important to ensure the needs of people with MND are addressed as early as possible, maximising quality of life and improving care planning.[2,12] However, diagnosing MND is often challenging. On average, diagnosis occurs 10–16 months after symptom onset, with delays commonly related to referrals to non-neurology services and issues recognising early signs.[15,16]

When someone is undergoing investigation for MND, and at the point of diagnosis, it's important that they, their family and carers have suitable support. This includes a clear point of contact for questions and access to appropriate information.

There is no single test to confirm MND. Diagnosis relies on medical history and physical examination, and investigations such as blood tests, neuroimaging and electrodiagnostic testing (such as electromyography, EMG) to exclude other possible conditions.[6,15,17,18]

As a GP, you play a key role in recognising concerning symptoms and arranging timely referral when MND is suspected. Referral should be made directly to a neurologist with expertise in MND.

Key point

To support earlier recognition, we have developed a Red Flags Tool in partnership with the RCGP. Its aim is to reduce referral delays by prompting GPs to look for additional symptoms and consider the possibility of a neurodegenerative condition. GPs are not expected to be able to make the diagnosis.

Download the Red Flags Tool at **mndassociation.org/redflag**

The NICE guideline on MND recommends that, if MND is suspected, the possible diagnosis should be specified in the referral letter. The GP should contact the consultant neurologist directly for an urgent review, similar to the cancer referral pathway, to avoid unnecessary waiting while a very serious diagnosis is being considered.[10]

NICE also advises that a person's GP should be informed when a neurologist suspects or confirms a diagnosis of MND and provided with information about the likely prognosis.[10]

Case studies

We have included a number of examples illustrating how people with MND, their carers and clinicians first noticed symptoms and navigated the diagnostic process.

See **mndassociation.org/mndviews** for more interviews with people with MND and carers about MND management.

Meena, carer for her father who's living with MND:

We weren't aware of the first symptoms of MND because my dad also has type two diabetes. We first went to the GP because he had a spot on his back, which can be a signs of neuro damage in type two diabetes. The GP referred us to a neurologist who conducted a lot of nerve tests, and told us that Dad has MND.

It was only after the diagnosis that we realised that he had started to have a lot of symptoms around a year before, such as slight tremors under the skin. We described them as if you see a little alien crawling underneath the skin. He had a lot of cramping, initially just in the legs, but it did eventually start to spread across the body. His symptoms predominantly started on the left-hand side. Initially, his shoulder was affected, and for a long time, he was constantly diagnosed with frozen shoulder, which just wouldn't go way. So after a year, we realised it just couldn't possibly be frozen shoulder and that's how we progressed.

David, 50 years old, was diagnosed with MND in 2025:

It was about 2022. A friend came to see me, and we decided to do a press-up challenge. I got on the floor, and I just went down. My arms couldn't support my own weight. I also remember that when I was driving, I couldn't grab the indicators on the left-hand side. Originally, they thought it was arthritis. When I kept persistently asking, the physiotherapist referred me to a neurologist.

I had three MRIs and a nerve conduction test, and I went to the appointment in March 2025. Here, they checked me out and asked a lot of questions about my family history. Then, they told me I have MND. It was a surreal moment.

I didn't really know much about the illness, and it was when I did a breathing test that I started to realised what this is all about. I had flagged up that my breathing wasn't very good. I was becoming short of breath, and I noticed it was worse when I lay flat. I was also having nightmares and waking up with headaches every morning, and they explained to me that those were signs that I wasn't getting enough oxygen into my bloodstream.

2

Managing MND symptoms

Mobility

MND causes most voluntary muscles to waste and weaken, resulting in loss of strength and function. Weakened muscles in the arms, legs, neck and torso can cause problems with movement, posture and co-ordination and affect balance, increasing the risk of falls.[19]

As muscle weakness progresses, everyday activities can become increasingly challenging. These include walking, using the hands or keeping the head up. Muscle weakness also make personal care difficult, including preparing food, eating and showering.[4] For this reason, people with MND might need support with most everyday activities and use wheelchairs and assistive equipment, such as orthoses and hoists. Home adaptations may also be necessary.

- Refer the person to a physiotherapist who can provide walking aids and support for posture, including exercise advice.
- Refer the person to an occupational therapist for equipment to help with daily living, such as environmental controls.
- Advise the person that mobility issues will affect driving, and they should inform the DVLA or DVA and their insurer after diagnosis.
- If there are problems maintaining personal care, refer to adult social care services to arrange external support.

Muscle problems

People may experience tightness and stiffness, which can lead to sudden, painful cramps and spasms.[9] See page XX for guidance on medications for cramps and spasms.

Muscle twitching (fasciculations) can be common.[4] These may feel like rippling sensations in individual muscles or across wider areas, and can be visible to others. They can become more pronounced when someone is stressed, although they usually ease over time. Fasciculations may also not be related to MND.

Speech and swallowing

Dysarthria

Over 80% of people with MND experience speech difficulties, known as dysarthria, due to weakness in the face, tongue, throat and breathing muscles. Speech may become slurred and quieter, and some people may lose the ability to speak entirely. Voice could also sound hypernasal, raspy or breathy.[20]

It can take a lot of effort to communicate, so people may feel isolated or frustrated. Tracheostomies can also make speech more effortful. Many people will use augmentative and alternative communication (AAC) systems, which may range from notepads and alphabet charts to high-tech aids such as text-to speech devices. People with cognitive changes may also have language issues and problems using communication aids.[3,9,20,21]

If you notice any changes in voice or communication, refer the person to a speech and language therapist. See the following tips to help you communicate with the person with MND during visits.

Do:

- find out how the person with MND prefers to communicate and any equipment they like to use
- find out if the person has a simple code for yes and no, such as, eye blinking or moving a finger. Be aware that the person may not be able to reliably use this method as the disease progresses, for example, if can't move their hands
- make sure any necessary communication aids are ready and easy for them to reach, including pen and paper. You can also use gestures, pointing and pictures to help communication
- encourage them to speak slowly and over-emphasise words to help clarity

- make sure the environment is calm, give the person time, check the lighting and reduce background noise where possible
- check back with them on what you think they said and admit it when you don't understand
- make it easier for them to reach you. If speaking on the phone is hard for them, they might prefer to use email or text messages
- encourage the person to note down, before the appointment, any points they wish to discuss. We also offer a range of forms to help them communicate their needs (see page xx).

Try not to:

- change how fast or loud you speak, unless the person with MND has asked you to
- finish their sentences, unless they've asked you to
- interrupt them – if the person uses assisted ventilation, they may have to speak in rhythm with the machine. Pauses while they are speaking won't always be natural pauses
- use family members or caregivers to translate for them unless that's what the person in your care wants
- use open questions if the person has significant issues communicating. Instead use closed questions that can be answered with yes, no or a single word.

Information to share:

Information sheet 7C — Speech and communication support
Tools — Communication card and Speech notepad

Information for professionals:

Video resource — Better conversations

See page 70 to order publications.

Dysphagia

Weakened bulbar muscles can cause swallowing problems, known as dysphagia. This affects at least two-thirds of all people with MND during the disease. It can make it difficult to eat, drink, swallow medications or saliva (see saliva issues on page XX).[22,23]

Dysphagia increases the risk of aspiration, as food, liquids or saliva may go down the airway. This can lead to recurrent chest infections and coughing, choking sensations or actual choking episodes.[22,23]

Key point

While these episodes are often distressing for both the person with MND and those around them, it's important to reassure them that death from choking is rare.

Problems with eating and drinking have a significant social and psychological impact. Dysphagia can also cause weight loss, malnutrition and dehydration.[22,23]

Functional consequences of weight loss and malnutrition include loss of strength, fatigue, impaired immunity (increasing susceptibility to infections) and poor skin health, including an increased risk of pressure sores.[23] Weight loss is also associated with a poorer prognosis.[22] Dehydration may contribute to bowel and bladder problems, such as constipation (see page XX).

Refer to a speech and language therapist (SLT) if you notice, or the person reports, any signs of dysphagia. These may include:[23]

- episodes of coughing and choking, or a sensation of choking
- inability to form lip seal or a bolus with the tongue
- difficulties moving the tongue or food around the mouth
- difficulties chewing and needing several swallows for a mouthful

— drooling and a wet or gurgly sounding voice

— reduced appetite, avoiding food, or frustration with eating.

If oral eating is no longer possible or sufficient, the SLT may recommend enteral feeding, such as gastrostomy.[5] This may not always be possible, for example in cases of severe respiratory insufficiency.[9] Early referral to a SLT is therefore essential, as they may recommend an early gastrostomy placement. Some people may also choose to never have a gastrostomy, which may be recorded in an Advance Decision to Refuse Treatment (see page XX). See the next page for information you may want to share with the person with MND who's making a decision on gastrostomy.

Help monitor weight loss and malnutrition and refer to a SLT and a dietitian without delays. Weight loss in MND may also be caused by other factors, including muscle wasting, mobility issues (such as difficulty holding cutlery) and cognitive changes that affect meal preparation.[9,24] An occupational therapist can advise on equipment to help with eating, such as adapted cutlery.

Provide guidance on medications that are easier to swallow (such as syrups) and/or suitable for tube feeding. See page XX.

Lorazepam may be considered for acute episodes of laryngeal spasms. These are involuntary contractions of the laryngeal muscles caused by swallowing issues. They can briefly stop someone from breathing or speaking and may be accompanied by stridors.[25] SLTs can also advise on managing these spasms.

Information to share:

Booklet — Eating and drinking with MND
Gastrostomy tube: is it for me? — **gastrostomychoice.co.uk**
MyTube — **mytube.mymnd.org.uk/**

See page 70 to order publications.

Medications

People with MND can take riluzole, which is the only licensed disease-modifying drug for MND in the UK. Specific symptoms, such as pain or drooling, may also require pharmacological treatments. Swallowing difficulties (dysphagia), caused by weakness in the muscles of the mouth and throat, may make it difficult to swallow tablets. The GP should advise on alternative forms of medications, such as patches and syrups.

Some people with MND may also use tube feeding. In this case, you should advise which medications are suitable for administration via the tube. Not all medications, including liquid medicines, are licensed for use via feeding tubes, and they may cause blockages. Crushing or dispersing medications that are not meant to be given this way can also make them unsafe or ineffective.[26]

Riluzole

Riluzole is a glutamate antagonist that has been shown to slow disease progression and extend survival in MND.[3] However, it does not reverse or stop disease progression, nor does it improve muscle strength.[27–29] People who take riluzole should be made aware that they will not feel stronger when taking the drug

Not all MND specialists support the use of riluzole due to its limited benefits. Nonetheless, riluzole is recommended by NICE guidelines and it has over 20 years of safe use, with rare significant side effects.[10] Side effects include elevated liver enzymes, lack of energy, nausea and gastrointestinal problems.[3,30]

Riluzole comes in tablet or liquid form for people with swallowing difficulties. A film which slowly dissolves on the tongue (orodispersible film) is also available.[3,31] The GP and the MND specialist should agree a shared-care protocol, under which the GP issues repeat prescriptions.

Baseline investigations include:

- liver function tests (including serum transaminases, bilirubin and/or gamma-glutamyl transferase)
- full blood count (including differential white cell count)
- urea and electrolytes.

After starting riluzole, full blood count and liver function tests should be undertaken:[32,33]

- every month for the first three months
- then every three months for the remainder of the first year
- annually thereafter to review the appropriateness of treatment.

Responsibility for prescribing and monitoring should be made clear in the protocol. Learn more on **england.nhs.uk/publication/shared-care-protocols/#heading-16**.

Complementary therapies

Although they provide no treatment for the disease, many people with MND use complementary therapies, such as aromatherapy, reflexology, massage, relaxation techniques and acupuncture. There is no controlled trial evidence of the benefits of these therapies in MND, but some people report improvements in wellbeing.[34,35]

It is important that the therapist has an understanding of MND, and that neither the person with MND nor the therapist has unrealistic expectations that complementary therapies will offer a cure.

Unproven treatments

Many people with MND explore unproven treatments. This may lead to false hope, wasting time and money, and possible adverse effects.[34] The MND Association co-funds an international group of scientists and clinicians, known as ALS Untangled, to investigate unproven or alternative treatments for MND. See **alsuntangled.com**.

Secretions

People with MND often experience saliva problems because of poor lip seal and/or impaired swallowing.[22] Issues include thin watery saliva that may lead to drooling (sialorrhoea), thick tenacious saliva that is difficult to clear from the airway, or a mix of thick and thin saliva.[40] In this case, it is recommended to address thick saliva first. People can also experience dry mouth at the same time.[9]

To manage saliva, first assess:

- the location, pattern, volume and viscosity of secretions
- how they are impacting the person and whether there are any co-morbidities.

This is essential to choose the right treatment, especially as some medications could dry up saliva, making it worse if it's already thick.[9] Our care pathway (see below) is an interactive tool designed to help you to assess and manage saliva-related symptoms. On the next pages, we summarised pharmacological and non-pharmacological management options from the pathway. For drug dosages, refer to British National Formulary or Palliative Care Formulary.

Further reading:

Information sheet P3 — Managing saliva
Information sheet P9 — Oral suction for MND
Care pathway — Saliva management

See page 63 to order publications.

Thick or tenacious saliva

First line non-pharmacological:

- Assess for reversible causes (reflux/oral inflammation/ chest infection).
- Review anticholinergic medications and stop them if possible.
- Ensure adequate hydration and advice to avoid caffeinated and alcoholic drinks.
- Trial steam inhalation/humidification/nebulisers.
- Trial papase (papaya enzyme) as a tablet or wiped around the mouth.
- Consider fresh pineapple/dark grape/papaya juice to thin saliva.
- Consider oral suction to remove thick secretions in the mouth. **NB.** This must be done with caution and requires appropriate training. See our relevant information sheet above to learn more.
- Consult with a **dietitian** regarding reducing or avoiding dairy products and if the person is taking oral nutrition support products.
- Refer to **occupational therapy** to advice on ways to ensure upright posture with trunk/head supports (such as neck collars).
- Refer to **specialist respiratory team** to regularly review cough augmentation to clear airways and advice on breathing exercises, including unaided breath stacking and active cycles of breathing techniques.

First line pharmacological:

- Carbocisteine – tablet or oral liquid.
- Acetylcysteine – effervescent tablet.

Second line pharmacological:

- Saline or hypertonic saline nebuliser.

Thin saliva or sialorrhoea

First line non-pharmacological:

- Recommend low foaming toothpaste free of sodium lauryl sulphate and/or a suction toothbrush for oral care.
- Try ginger or sage tea, or dark grape juice (it may reduce the effect of anticholinergics).
- Consider an oral suction unit for drooling (requires training).
- Encourage regular swallowing. Prompt apps are available on Apple/Android. Refer to a SLT for techniques on swallowing if the person has dysphagia.
- Refer to occupational therapy to advice on ways to ensure upright posture with trunk/head supports (such as neck collars).

First line pharmacological: The following medications have possible central nervous system (CNS) side effects. Consider them if these side effects are unlikely to be harmful.

- Amitriptyline – tablets.
- Hyoshine hydrobromide – tablets or patch.
- Hyoshine butylbromide – tablets.

First line pharmacological: If CNS side effects may be harmful (for example, if there are cognitive issues or in elderly people), consider:

- Glycopyrronium bromide – solution or tablet.
- Atropine 1% drops, used under the tongue – drop onto a spoon first to avoid accidental overdose.

Second line pharmacological: Refer to a specialist service for Botulinum toxin A. Be aware that increasing dysphagia may be a side effect of Botulinum toxin A, so some suggest only resorting to this treatment if the person already has an enteral feeding tube in situ.

Third line: Consider further MDT discussion with specialist services, such as the MND Care Centre, ENT or radiotherapy.

Dry mouth

- Review medications that could cause dry mouth and consider alternatives or adjustments, if appropriate.
- Liaise with the respiratory team if the person uses non-invasive assisted ventilation, which may cause dry mouth.
- Ensure the person is well hydrated. Encourage frequent sips of water or use of ice chips (check swallow safety).
- Recommend to swill the mouth throughout the day. Oils such as ghee, butter, olive oil and coconut oil can be used to moisturise the mouth, either swabbed around the mouth or swilled (oil pulling).
- Advice to limit caffeine and alcohol intake, and to use sugar-free gum or lozanges if swallowing is safe. Seek advice from a SLT.
- Advise regular lip balm application to prevent drying/cracking.
- Recommend artificial saliva substitutes (sprays, gels, lozenges).
- Educate about mouth breathing. Explain how habitual mouth breathing contributes to oral dryness. Seek advice from respiratory services if the person has breathing issues.
- Suggest humidifier use, especially overnight.

Encouraging good oral hygiene is also important. Tips include:

- twice-daily brushing with fluoride toothpaste, and a soft-bristled brush to prevent gum irritation
- low foaming toothpaste free from sodium lauryl suplhate and alcohol-free mouthwashes
- flossing or using interdental brushes if dexterity allows
- tongue cleaning with a scraper or toothbrush to reduce bacteria and improve oral freshness
- an electric or suction toothbrush if motor function is limited.

The person may need help from a carer to maintain oral hygiene, for example if they have muscle weakness in the arms and hands.

Weak cough

Weakness in the breathing and bulbar muscles can result in a weak cough. This can make it difficult to clear aspirated food, drinks, saliva or other secretions (such as mucous) from the lungs and airways. This increases the risk of aspiration and chest infections. Respiratory tract infections and pneumonia may also trigger acute breathlessness.[37]

Assess cough effectiveness by measuring peak cough flow (PCF).[10] PCF > 270 L/min is normal. PCF>160 L/min is required for an effective cough and less than 270 L/min is associated with increased risk of secretion retention and infection.[38,39] A PCF between 160–270 L/min should prompt referral to a specialist respiratory physiotherapist to improve cough effectiveness.

Breathing

Weakening of respiratory muscles, particularly the diaphragm, causes breathlessness, especially when lying flat, and respiratory insufficiency. In most people with MND, this arises in the later stages and it is usually the cause of death in MND.[3,37,40] However, for some people, respiratory symptoms may be the presenting ones.[37]

The NICE guideline on MND describes the following as signs and symptoms of potential respiratory impairment:[10]

Symptoms	— Breathlessness — Orthopnoea — Recurrent chest infections — Disturbed sleep — Nightmares — Daytime sleepiness	— Poor concentration and/or memory — Confusion/hallucinations — Morning headaches — Fatigue — Loss of appetite
Signs	— Increased respiratory rate — Shallow breathing — Reduced chest expansion on maximal inspiration	— Abdominal paradox — Use of accessory muscles of respiration — Weak cough — Weak sniff

Recommend vaccinations. These may include flu, coronavirus and pneumococcal vaccinations. Visit **mndassociation.org/treatments** to learn more about vaccination eligibility for people with MND.

Refer the person without delay if you notice any respiratory signs or symptoms. The specialist respiratory team may recommend assisted non-invasive ventilation (NIV) or a tracheostomy.[37] If the person already uses assisted ventilation and reports any problems, they should be referred to the respiratory specialist team.

The development of respiratory symptoms often has implications for increasing dependency and end-of-life decisions. Referral to palliative care may therefore be appropriate. The district nurses and occupational therapists can advise on supportive equipment to assist with respiratory management, such as profiling beds.

Prescribe medications when necessary. Antibiotics are recommended for respiratory tract infections.[46] Opioids should be considered to relieve symptoms of breathlessness.[10] Benzodiazepines may also be helpful when breathlessness is exacerbated by anxiety.

Key point

Oxygen may lead to a life-threatening buildup of carbon dioxide. For this reason, oxygen should not be used to treat breathlessness in MND, unless recommended by the palliative care or respiratory consultant working with the neurologist.[41,42]

A proportion of people with MND experience central brainstem respiratory drive failure.[43,44] These people may be particularly sensitive to even low doses of benzodiazepines and opiates, so careful monitoring is essential.[45]

Non-motor symptoms

People with MND experience various non-motor symptoms, including pain, fatigue, constipation, urinary urgency, cognitive and behavioural changes, emotional lability and secretion issues (see page XX for saliva management).

Pain

Motor neurones do not transmit or change pain signals, so MND itself is not usually painful. However, people may experience aching, tenderness and other types of pain, such as:[47–49]

- spasms, stiffness and cramps in the lower limbs, hands and abdomen
- neuropathic pain such as burning or shooting pain
- joint pain and contractures due to reduced mobility
- pain in the back, shoulders and neck due to loss of muscle strength and mobility
- pressure sores, itch and oedema (fluid retention)
- skin lesions, facial pressure sores and ulcers on the nasal bridge caused by the mask used for non-invasive assisted ventilation
- pain due to suctioning of secretions and a tracheostomy tube irritating or weighing on the throat.

Pain intensity does not depend on how long someone has had MND.[47,50] It is often experienced as episodes of moderate intensity, which may fluctuate or suddenly worsen. It can also be persistent, especially towards the end of life.

Pain in MND may be overlooked or under-reported. A person may not say that they are in pain because they might feel that it's not as important as other symptoms, or that nothing can be done. It's important to ask them about pain during visits and to assess its cause. It may not be possible to completely eliminate pain, but management strategies can improve quality of life.[49,50]

Prompt referrals for non-pharmacological management:

- to a physiotherapist to improve mobility and range of movement, including passive or active exercises.[10,47,50]
- to an occupational therapist for advice on equipment for reduced movement, such as hoists.[47,50]
- to orthotists, physiotherapists or occupational therapists for orthoses to help with joint pain, such as neutral-position hand splints.[47,50]
- to a complementary therapist for massages and relaxation techniques.[47,50]
- to the respiratory team if the person uses non-assisted ventilation or has a tracheostomy, and these are causing pain.

Prescribe medications, considering the person's needs and preferences, including any swallowing issues. Traditional analgesics such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) are likely to be beneficial. Opioids may also help, and with careful titration, excessive drowsiness and respiratory depression can be avoided.[10,48,49].

- Neuropathic pain: offer a choice of amitriptyline, duloxetine, gabapentin or pregabalin as initial treatment. If the initial treatment is not effective or is not tolerated, offer one of the remaining three drugs, and consider switching again if the second and third drugs tried are also not effective or not tolerated.[51]
- Joint pain: use simple analgesia, such as long-acting NSAIDs.[50] Gastroprotection may be necessary when prescribing NSAIDs.[52]

- Muscle cramps: consider quinine as a first-line treatment. If quinine is not effective, not tolerated or contraindicated, consider baclofen as a second-line treatment. If baclofen is ineffective, not tolerated, or contraindicated, consider tizanidine, dantrolene or gabapentin.[10] Some clinicians also find magnesium or mexiletine to be helpful options before trying baclofen.[47,50]
- Muscle stiffness, spasticity or increased tone: consider baclofen, tizanidine, dantrolene or gabapentin. If these are ineffective, not tolerated or contraindicated, consider referral to a specialist service for treatment of severe spasticity.[10]

Benzodiazepines such as diazepam may be helpful for some people to treat spasticity, though these have a stronger sedative effect.[47] Injection of botulinum toxin into large muscles may also help.[49]

Consider that some people with MND may rely on muscle stiffness to help them stand or walk. Reducing stiffness too much may make it harder for the person to move. Therefore, the dosage of muscle relaxants such as baclofen should be carefully adjusted to avoid increased weakness and decreased mobility.[50,53] Close monitoring is essential when prescribing muscle relaxants with opioids, as this combination could cause dangerous drug interactions.[54]

Additionally, check whether the person is taking any statins, as these medicines can sometimes cause muscle pain and weakness. You may review the need for statins, adjust the dose or recommend alternatives if side effects are suspected.[55,56]

Further reading:

Information sheet P11 – Pain in MND

See page 70 to order publications.

Skin sensitivity[50,57]

- Good skin and pressure care are vital. People with MND may need help to adjust their position. This must be done with extra care and following advice from a physiotherapist.
- Refer to an occupational therapist for advice on equipment for skin sensitivity relief, such as a bed cradle to relieve the weight of bed clothes and a pressure-relieving mattress and cushions.
- Advise warm socks for cold feet and lightweight bed clothing.
- Consider emollients or antihistamines if itching is an issue.

Oedema (fluid retention)[58]

Restricted activity and posture may cause fluid retention.[62]

- Refer to an occupational therapist and a physiotherapist to assess posture and seating and maximise movement.
- Compression support stockings, effleurage (light massage) and reflexology may be beneficial.
- Diuretics are rarely helpful as they can promote urinary urgency and electrolyte disturbance.
- Refer to the lymphodema service, if it's available in your area.

Constipation and urinary problems

Although MND does not usually affect bowel and bladder functions, mobility problems can make it more difficult to access and use the toilet. People may also worry about not getting to the toilet in time and therefore think drinking less will help with this.

However, not drinking enough can irritate their bladder. This can cause urine infections and actually make them feel that they need to go to the toilet more often. Dehydration can also cause constipation, which may make emptying the bladder and bowels hard. Medications, changes in eating, poor mobility or breathing issues can also cause constipation.

- An occupational therapist can recommend equipment and adaptations to access the toilet more easily. You may need to arrange for care workers if the person is having difficulties with personal care.
- Encourage wearing loose, light clothing that's easy to remove
- Suggest considering incontinence products such as disposable pads and matters protectors. In case of any accidents, cleaning foams and barrier creams can help prevent skin problems and discomfort.
- Suggest establishing a routine, like sitting on the toilet 15–20 minutes after breakfast, to facilitate regular bowel function
- Stool softeners and stimulants may be helpful for constipation, and liquid versions are available if swallowing is impaired. Suppositories, enemas, or manual evacuation may be necessary.[59]
- Bulking agents and fruits high in sorbitol (such as prunes) may also help, but caution is needed, as some foods can increase the risk of choking. Stringy, fibrous, coarse, hard or sticky foods, as well as some fruits with skins, may be difficult or unsafe to swallow.[24,60] Always consult an SLT and a dietitian on safe ways to maintain fibre and hydration intake.

Fatigue

Encourage the person to keep track of their energy levels and how they feel after different activities. This can help them identify which tasks leave them tired and plan their schedule accordingly. External support from care workers can also help. For example, the care worker could complete certain tasks so that the person with MND can save energy for other activities that matter most to them.

Emotional lability[9,61]

Emotional lability is also known as pseudobulbar effect. It causes involuntary reactions that do not reflect what the person feels, such as laughing when in pain. These reactions may be upsetting or seem unfeeling. They may also be misinterpreted as a behavioural symptom or depression, but they are independent of them. Reassuring people that emotional lability can be part of MND can help them manage its impact.

Treatment may be needed to reduce the frequency and severity of episodes. This may include off-label use of tricyclic antidepressants, such as amitriptyline, and selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine, citalopram and sertraline. Dosages are usually lower than those used for depression. Be aware also that there might be side effects and medications may not always be effective.

Cognitive and behavioural changes

Cognitive and behavioural changes affect about 50% of people with MND. This figure rises to 80% in the late stages of the disease.[62,63]

While for some people these changes may be mild, for others, they can be more severe. Up to 15% of people can also be diagnosed with frontotemporal dementia (FTD). This form of dementia is characterised by significant personality shifts, executive dysfunction, behavioural problems and language issues. Some people may show delusions, hallucinations, paranoia, depression or mania.[21]

Be aware that up to 15% of people initially diagnosed with FTD, go on to develop MND. In these cases, signs of dementia appear before (and may mask) MND motor symptoms.[64]

The following table summarises cognitive and behavioural changes.[21]

Executive dysfunction	— difficulties learning new things, including new therapies or equipment — managing everyday tasks (such as cooking, getting ready in the morning, driving, managing finances) — making decisions and planning for the future. People with severe changes and FTD may lack mental capacity. — concentration.
Language problems	— impaired verbal fluency, problems finding words, using short or incomplete sentences — repeating words no longer relevant or appropriate, or that someone else has just said — misunderstanding sentences or words.

Social cognition issues	— understanding other people's feelings and facial expressions, especially negative ones
Behavioural problems	— apathy and inertia (including loss of interest in others and inability to initiate activities) — loss of empathy and egocentric behaviour — disinhibition and loss of self-control — rigid and compulsive behaviours — changes in eating habits, such as cramming food (which may increase risk of choking). — people may also become more irritable and aggressive, and may lack insight.

Monitor any changes. Often, carers and relatives are the ones noticing that the person is not "who they were before". They may say that they are acting oddly or stubborn or seem uncaring and distant. You may also notice some of these behaviours during visits. For example, if the person seems uninterested while you are discussing a procedure that concerns them.

Consider using screening tools to identify cognitive and behavioural changes. Formal training and supervision by a neuropsychologist are recommended. Validated tools that take 5–20 minutes include:[65]

- Edinburgh Cognitive and Behavioural ALS Screen (ECAS): **ecas.psy.ed.ac.uk/**
- ALS Cognitive Behavioural Screen ALS-CBS): **tandfonline.com/doi/full/10.3109/17482961003727954?scroll=top&needAccess=true**
- MiND-B: **ativar.co.uk/en/outcome_measures**
- ALSFTD-Q: **eprovide.mapi-trust.org/instruments/amyotrophic-lateral-sclerosis-frontotemporal-dementia-questionnaire**

Refer to a neuropsychologist for a formal assessment if you notice any signs of cognitive and behavioural changes.[10] If changes are severe, formal assessments should be prioritised as there could be adult and child safeguarding issues.

Anticipate advance care planning as changes in cognition and behaviour can affect decision-making, independence and the ability to comply or cope with interventions, such as assisted ventilation and communication aids.[66,67] For this reason, the whole MDT should be alerted without delay to plan care accordingly.

Refer for a mental capacity assessment if the person is having problems making a decision. For example, if the person does not understand their options after they have been explained in an accessible way. Assessment must be carried out by a trained professional in line with the Mental Capacity Act 2005.

Support carers and families. Cognitive and behavioural symptoms can be very upsetting, significantly impacting the wellbeing of relatives and increasing the burden on carers.[66,67] It's essential to reassure carers and relatives that the person's behaviours are not personal. A carer's needs assessment, respite support and mental health support may be necessary. Be aware that the relationship between the carer and the person with MND may break down and external care support may be needed.

Treat other factors that may affect cognition and behaviour. These may include infections (such as pneumonia), low mood and depression, emotional lability (see page XX), or inadequate ventilation.[10,22,61] In this case, refer the person to the local respiratory team.

Emotional needs

MND poses psychological challenges for both the person with MND and those close to them, including children.[68] These include:[68]

- adjusting to the diagnosis – may bring up mixed emotions such as anticipatory grief, relief, hopelessness, anger or denial
- coping with uncertainties, including the variability of MND progression. This may bring up fears and anxieties, such as "I am a burden on my family" or "How am I going to die?"
- adapting to changes and losses – it can make people feel they're losing their sense of self or unable to enjoy meaningful activities like family outings and hobbies, leading to isolation and frustration
- coping with aids, adaptations and interventions. These can also cause financial worries.

People can also experience depression, which can further undermine quality of life, increase the risk of social withdrawal and reduce survival.[11,68,69] It can also mask behavioural changes, such as apathy.

Distinguishing behavioural problems from depression is essential to provide the right treatment. You can screen for depression with the Hospital Anxiety and Depression Scale (HADS) or the PHQ-9.[70,71] However, these tools include measures of physical symptoms, such as fatigue, which are common in MND and could affect test results. Consider adapting the tool or using the PHQ-2.[72]

Provide support. This includes signposting to information to help them understand what to expect. We also offer peer support groups, and our MND Connect Helpline can provide guidance (including on financial matters) (see page XX).

Refer to mental health services. The palliative care team can also provide psychological and spiritual support, and help planning for end of life.[3] This, although upsetting, can relieve some anxieties about future arrangements.

Prescribe medications such as antidepressants and/or anxiolytics if necessary.[11] Consider alternative forms of medications if the person has difficulties swallowing pills or uses tube feeding.

Provide evidence for benefits. People with MND, as well as their carers or relatives, may be entitled to financial help due to the condition. Help with this can relieve practical stress. See page XX.

Assess the wellbeing of carer, relatives and children. They may need to be referred to psychological support.[11] We also offer services to support carers and families affected by MND, including free counselling for children and young people through our partnership with Bernardo’s. Learn more on page XX.

Discussing suicide and assisted suicide

You may be asked questions about suicide and assisted suicide. People with MND may consider suicide for fear of what will happen as the condition progresses. It is important to let the person know that thoughts of suicide are not unusual among people with MND.[73] It can help to know that they are not alone and to have someone to talk about these thoughts and explore the reasons behind them. If suggestions or solutions to concerns can be provided, thoughts about suicide may subside.[74]

Active plans to commit suicide should always be taken seriously. Consider the use of suicide risk assessment tools to guide you.

At the time of publication, it is not legal for someone to:[75]

- encourage another person towards suicide (including advising them how to do this)
- assist them with their suicide.

It is legal for a person to decline or discontinue life-sustaining treatments which they feel are not helping or have become a burden. They can also record their choices with an ADRT. Medications cannot be used to hasten death.

3

Palliative and end of life care

Early palliative care

Establishing early links with palliative care can provide valuable support for people with MND and their families. The person with MND should be informed at diagnosis about local palliative services and how to contact them. Access to palliative care should be facilitated for people with current or anticipated complex needs, including social distress and rapidly progressing symptoms.[10]

This can be challenging as people may associate palliative care with immediate death. It's important to explain that this service can offer a wide range of support for both the person and their family since diagnosis.

As a GP, you should:

- Introduce palliative services via day care, respite, complementary therapies and hospice referrals.
- Add the person with MND to your local palliative care register to support co-ordinated care, and inform the district and community nurse that there is a person with MND in their area.[76]
- Discuss with the person their wishes, preferences and expectations for end-of-life care (see the next heading on advance care planning).
- Work with the person with MND and the rest of the care team to create a care plan that enables the person to live and die as they choose. This can also help to avoid unplanned hospital admissions.
- Support family members and carers (see page XX). They should be involved in decisions about treatments and care to the extent that the person with MND wants.[76]
- Provide medications and support to manage symptoms at end of life, in line with local palliative care guidelines (see page XX).
- Help the person with MND fast-track their applications to financial benefits (see page XX).

Advance care planning

Discussions about future care and end-of-life preferences should be held before the need becomes urgent. This allows people more time to think things through and consider their options. It may be overwhelming at times, but it can also help them maintain a sense of control.

The NICE guideline on MND recommends offering opportunities to discuss end-of-life care at trigger points. These include at diagnosis, if there is a significant change in respiratory function, and when discussing gastrostomy or non-invasive ventilation.[11]

It's important to take into account the person's communication abilities, cognitive status and mental capacity. If these are expected to get worse, consider discussing advance care planning at an earlier opportunity.[10]

Everyone should be assumed to have the capacity to make their own decisions, unless proven otherwise. If you see someone having difficulties with a decision, a trained professional should conduct a formal mental capacity assessment specific to that decision. Information should always be provided in an accessible way, with reasonable adjustments as needed. This may include communication or hearing aids, using pictures, or choosing a quiet place to talk without distractions.[77,78]

People may wish to discuss and plan for:[10]

- what they want or do not want to happen, such as their preferred place of death and use of anticipatory medicines. Some people may want to die at home. This will not always be possible, nor is it everyone's preference. For instance, a person may not wish to die at home if children live there
- who they want to involve in decision-making and who will represent their decisions, if they become unable to do so
- what should happen if they develop an intercurrent illness

- relevant advance care planning documents, including Advance Decisions to Refuse Treatment (ADRT), Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders and Lasting Power of Attorney (LPA) (see below).

Any discussions and decisions should be clearly documented and communicated to the MDT and ideally compiled into a personalised advance care plan. Out-of-hours primary care and ambulance services should also be informed of any DNACPR or ADRT.

The person should regularly be offered the opportunity to review and update their decisions, as preferences may change as the condition progresses.[10] Updated advance care documents should be included in the shared record. Also, advise the person to keep copies of these documents in a known location, so they can be used in emergency situations or by the carer/care workers.

Advance care plan: It can include any information the person considers important for their future needs, such as their values, medical choices, messages or arrangements for pets.

These preferences can also be recorded as advance statements, either within the advance care plan or as standalone documents. Advance care plans and statements are not legally binding but they should guide professionals, carers and other representatives when the person is unable to make or express their own decision.[79]

ADRT:[78] It's a legally binding document that allows the person to specify which treatments they do not want, or want to stop, and under what circumstances. This includes life-sustaining treatments such as assisted ventilation or antibiotics. It is only valid if the person has lost the ability to make a decision.

DNACPR: This document applies only to cardiopulmonary resuscitation. In England and in Wales, a DNACPR is not legally binding unless it is included in an ADRT with clear instructions about when it should be applied.

LPA:[78] It allows a person to choose who can make decisions on their behalf if they lack the capacity to do so. In England and Wales, it can cover decisions about finances, property and personal welfare, including healthcare and consent to medical treatments. It's important to discuss which decisions the person wants the attorneys to make. In Northern Ireland, the LPA is known as an Enduring Power of Attorney (EPA) and covers only financial and property matters.[80]

Talking about plans for end of life

Be prepared: Are you familiar with their disease progression, family situation and support network? Do they live alone?

Be mindful of time and place: These conversations can take time and may need to take place over several visits. It may be appropriate to pause or postpone the conversation if the place does not feel right, or if the person is not ready or does not have the energy to talk.

Don't assume: Avoid assuming what the person knows or wishes to discuss, and be mindful of information overload. Focused open questions can help guide the conversations. For example, instead of asking "How are you doing?", try "Do you have any concerns about X?" or, more specifically, "How's your pain at the moment?"

Acknowledge their feelings: Take time to acknowledge and validate the person's feelings, without making assumptions. Sometimes, they may hint at a concern, without feeling able to start talking about. Try saying: "I noticed when you said X, how is this affecting Y?".

Be flexible: Planning what to discuss can help. However, the person may want to discuss something else or not feel ready to talk. Be prepared to adapt the conversation to their needs and priorities.

Use non-verbal communication: Non-verbal cues such as nodding, maintaining eye contact and open body language can help the person feel listened to and facilitate engagement. Be aware, however, that people with MND may not always be able to show non-verbal cues, for example due to fatigue or difficulties maintaining posture.

Providing evidence for benefit applications

People with MND may apply for disability and employment benefits, and you may be asked to provide medical evidence to support their claims.

To ensure claims are dealt with quickly and with a greater chance of success, it's essential to carefully consider your wording. This should highlight the progressive nature of MND and how changes in the condition may occur rapidly.

It's also important to provide details to capture the complexity of the needs of people with MND. For example, instead of saying "Mrs Y has upper limb weakness and needs help with dressing", consider saying: "Mrs Y has upper limb weakness and is unable to dress without assistance. Even with help, it takes an hour to dress. She needs to stop for rests continually, as it is very tiring for her and causes significant pain in her arms and shoulders."

The disability benefits system is complex, and people with MND may not know what they are eligible for. Signpost them to our benefits advice service at **mndassociation.org/benefitsadvice** for guidance and share the information resources listed at the end of this section.

People with MND may also be eligible for NHS Continuing Healthcare (CHC), which can fund health and social care services to meet the extra needs of living with a disability. This care package is only available to people assessed as having a primary health need. The CHC assessment process can be lengthy, complex and burdensome. MDT support is essential to help the person access this vital support and to provide detailed evidence of their needs. Learn more on **mndassociation.org/chc**

Special Rules for End of Life[81]

In April 2023, the “Special Rules for Terminal Illness” were replaced by the “Special Rules for End of Life (SREL)”. These allow people who are thought to be in the last 12 months of life to access certain benefits more quickly, receive higher payments, and avoid a face-to-face medical assessment.

It applies to the following benefits:

- Attendance Allowance (AA)
- Personal Independence Payment (PIP – this has replaced Disability Living Allowance for new and existing claimants born after 8 April 1948)
- Disability Living Allowance (DLA – only available via reassessment for claimants who were aged 65 or over on 8 April 2013)
- Employment and Support Allowance (ESA)
- Universal Credit (UC).

If someone wishes to claim under SREL, this should be stated at the start of the claim. They will be asked whether they have, or are going to get, an SR1 form, which should be submitted with the claim. This form, known as BASRiS in Scotland, can be completed by a GP, a neurologist or a specialist nurse to show the person’s eligibility.

The form can be returned to the Department for Work and Pensions (DWP) by you or the person with MND online, by post or by email at form.e-SR1@dwp.gov.uk.

For DLA, PIP and AA, claims under SREL can be made on someone’s behalf without their knowledge, which can be helpful if the person can’t handle the claims process. For UC and ESA, only an appointee or a person who has power of attorney can make the claim on the person’s behalf.

As MND is a terminal, rapidly progressive disease, people with this condition are eligible to claim under the special rules. However, completing the prognosis section of the SR1 form can feel challenging as MND progression is unpredictable.

A third of people with the condition die within a year of diagnosis, and more than half die within two years, although some people experience slower progression.

Nevertheless, DWP guidelines state that "you should complete an SR1 form if you have a person in your care who has a progressive disease and, as a consequence of that disease, you would not be surprised if they were to live for less than 12 months."

There are no negative consequences for you or the person in your care if someone claiming under the special rules lives longer than expected. If the claim is successful, the award may be given for up to three years before reassessment.

To learn more visit **gov.uk/government/publications/dwp-factual-medical-reports-guidance-for-healthcare-professionals/the-special-rules-how-the-benefit-system-supports-people-nearing-the-end-of-life**.

Information to share:

Information sheet 10A – Benefits and entitlements
Service – **mndassociation.org/benefitsadvice**

See page 70 to order publications.

End of life care

The most common cause of death in MND is respiratory failure, often with additional chest infection. It is very important to reassure people with MND and their carers that death from choking is rare.[8]

Recognising when a person is entering the dying phase can be difficult, as the trajectory varies. For some, it can be rapid. Common symptoms towards the end of life include shortness of breath, pain and anxiety.

Signs that death may be approaching can include deterioration in respiratory function (including increased secretions, more frequent infections and increased dependency on NIV), difficulty swallowing and digesting enteral nutrition, weight loss, oral complications, skin breakdown and the need to more frequently adjust medications to control symptoms.[8,82]

When a person is thought to be entering the last days of life, this should be clearly communicated, and care should be personalised and delivered in line with their wishes.[83,84] It's essential to establish and provide as early as possible the resources needed by the person with MND, including specialist palliative care.[10,84]

Ongoing assessment

Monitor and review symptoms regularly, including:

- pain and pressure care
- respiratory symptoms
- dysphagia and hydration status
- oral secretions and dry mouth
- increased fatigue, insomnia and lost of appetite
- anxiety, delirium and agitation
- bowels and bladder.

Advise on non-pharmacological measures where appropriate, such as using a fan to relieve breathlessness, ice lollies to help with dry mouth, and regular re-positioning for pressure care and pain relief. Ensure timely access to any relevant equipment, including a riser-recliner chair, hospital bed, commode and a suction machine.[10,84]

If there are concerns that the person is thirsty and hydration via feeding tube is not available, subcutaneous fluids may be considered as a trial. If this is necessary, an inpatient admission might be required, though this is rarely needed.[84] Ensure thorough and regular mouth care is given as this can impact on the perception of thirst. The mouth should be kept clean and moist, for example using a soft baby toothbrush.

Agitation before death is common and can happen persistently or intermittently. This can be distressing for families and carers, so it's important to reassure them. Ensure also that there is no physical cause for the agitation, such as pain or discomfort and consider medications when necessary (see the next page).

Wishes, communication and cultural needs

Explore the wishes of the person with MND and those close to them, including preferences for symptom management, spiritual beliefs and care needs after death.[84]

Seek specialist advice to support informed and shared decision-making. If the person is using NIV, they can request withdrawal at any time. If they want to stop it, the procedure should be led by a palliative care specialist. If a person reliant on ventilation is approaching end of life, death is likely to occur within a relatively short time after withdrawal. Medication can be used to relieve anxiety and distress.[10]

If any preferences or wishes can't be met, communicate this sensitively and explain the reasons. Communication may become extremely difficult at this stage, but every attempt should be made to maintain it.[82] Ensure access to suitable communication methods and use yes/no questions, picture/alphabet boards and eye movements.[10]

Be aware that cultural and spiritual needs may influence end-of-life preferences. Further resources include:

- the Culturally sensitive end of life care toolkit created by NHS Birmingham and Solihull: **birminghamsolihull.icb.nhs.uk**.
- the Faith at end of Life guide by Public Health England: **gov.uk/government/organisations/public-health-england**.

Family and carer support

Assess the needs of carers and family members. Additional social care and nursing support may be necessary to reduce caring tasks and enable them to spend more time with the person with MND.[10,83,84] Offer ongoing bereavement support.

Anticipatory prescribing

Prescribe anticipatory medications as early as possible for symptoms likely to occur. Discuss any prescribing needs with the person with MND, the MDT, carers and relatives, and inform them of how medications might affect the person.[84] For example, if sedation may limit communication, the person may wish to have important conversations as soon as possible.

The NICE guideline NG31 on care of dying adults in the last days of life recommends stopping any previously prescribed medications that do not provide symptomatic relief or that may cause harm.[84]

To administer medications, the guideline recommends using subcutaneous or intravenous routes rather than intramuscular injections. Consider a syringe pump for continuous symptom control if more than two or three doses of “as required” medicines have been given within 24 hours.[84]

Consider the medications on the next page for anticipatory prescribing.[84] For dosages, refer to the British National Formulary or Palliative Care Formulary. See page XX for what to consider when prescribing medications to a person with swallowing issues.

- Pain: onalgesics, including opioid analgesics with careful titration to avoid excessive drowsiness and respiratory depression.[48,85] See also page XX.
- Breathlessness: an opioid or a benzodiazepine (these may have a strong sedative effect).[10,84] A combination of an opioid and benzodiazepine may also be considered, but requires careful monitoring for signs of respiratory depression.[45,84] Do not prescribe oxygen, unless recommended by the palliative and respiratory teams.[41,42,84]
- Nausea: anti-emetics.[85]
- Anxiety, delirium or agitation: a trial of benzodiazepine to manage anxiety or agitation. A trial of antipsychotic medications may help manage delirium or agitation.[84,85]

See page XX for managing secretions and dry mouth.

Information to share:

Booklet — End of life: a guide for people with MND
Information sheet 14A — ADRT and advance care planning

Information for professionals:

Booklet — Advance care planning for MND
Booklet – A professional's guide to end of life care in MND
RCGP – End of life and palliative care toolkit
elearning.rcgp.org.uk/mod/book/view.php?id=12529

See page 70 to order publications.

Supporting families and carers

MND affects the whole family, so it is essential to provide both emotional and practical support. Many people providing care do not identify themselves as carers and may be unaware of the support or benefits they are entitled to. Identifying their needs and offering advice is important for their psychological and physical wellbeing.

Be aware that some people with MND may not have family to support them or a carer. Others may experience relationship breakdown as MND progresses. In these situations, people with MND may have additional emotional and practical needs, including earlier referral to adult social care or paid care workers to support daily activities.

- Make sure the person's role as a carer is recorded on both their own GP record and the record of the person with MND. This will help them access the support they are entitled to, including financial benefits and health checks.
- Provide emotional support and referral to psychological support.
- Signpost them to our services, including our MND Connect Helpline, information resources and benefits advisors for guidance on financial support for carers and families (see page XX).
- Carers may feel very isolated and may benefit from being in contact with other carers of people with MND. The MND Association can sometimes provide volunteers to visit at home, and our local branches run local peer support meetings.
- Anticipate carers' needs to help prevent burnout and arrange for a formal carers' needs assessment with the local social services.
- Arrange respite care. Respite may be provided at home, in a day centre, hospice or residential setting.
- Refer the family to palliative care services to provide ongoing support, including bereavement care. Our online bereavement hub can also help: **mndassociation.org/bereavement**.

Supporting young people

It’s essential to identify whether there are children or young people affected by MND, as families may need targeted practical and emotional support. In some cases, there might also be safeguarding concerns.

- Help the family explain MND to children. Our online hub for children and young people affected by MND offers age-appropriate information for those aged 4–25 to help them understand what is happening. **mndassociation.org/cyp**
- Consider referral to the school nurse or Child & Adolescent Mental Health Service (CAMHS). We also offer free counselling through our partnership with Bernardo’s: **mndassociation.org/cyp**.
- Refer to social care services for an early help assessment (EHA). This can identify the current and future needs of children/young people, the support the family needs to care for them, and whether they may become young carers.
- Arrange a young carer’s needs assessment.

Information to share:

Booklet — Caring and MND: support for you
Information sheet 10G — Support for families with children

Information for professionals:

Booklet — Supporting children and young people affected by MND
Infographic – Think family

See page 70 to order publications.

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How we can support you

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide information about our services mentioned below.
Email: mndconnect@mndassociation.org
Tel: 0808 802 6262

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for health and social care professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals’ Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of support funds for people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on research for people with or affected by MND.
mndassociation.org/research

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We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to **education@mndassociation.org**.

If you would like to help us by reviewing future versions of our information resources, please email us at **education@mndassociation.org**.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call **0808 802 6262** or email **mndconnect@mndassociation.org**.

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**Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.**