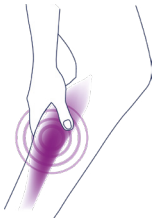


Pain in motor neurone disease

Motor neurone disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to weakness, stiffness and loss of muscle mass, causing difficulties with movement, breathing, swallowing and speaking.[1,2]

People with MND may also experience a range of non-motor symptoms, including cognitive changes and pain. These can complicate MND management and affect quality of life.[2]

This information sheet explains how pain can affect people with MND, what can help, and where to find further information and support.

Information to share with people with or affected by MND:

Information sheet 11E - *Managing pain*

Download at **www.mndassociation.org/publications** or contact MND Connect. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

Is MND painful?

Motor neurones do not transmit or change pain signals, so MND itself is not usually painful.[3] However, people may experience discomfort and pain at any stage of MND, including early on. Its intensity does not depend on how long someone has had MND.[3,4,5]

Pain can significantly impact someone's quality of life. It can affect their daily activities, mood, sleep, relationships and overall enjoyment of life.[3,6] It also increases the likelihood of depression, which can further worsen the person's quality of life.[4,7] A psychologist can advise on how to manage any underlying causes of depression and cope with feelings such as anxiety and stress.

Pain is often experienced as episodes of moderate intensity, which may fluctuate or suddenly worsen.[3,5] However, it can also be persistent, especially towards end of life, when it may become more severe.[4]

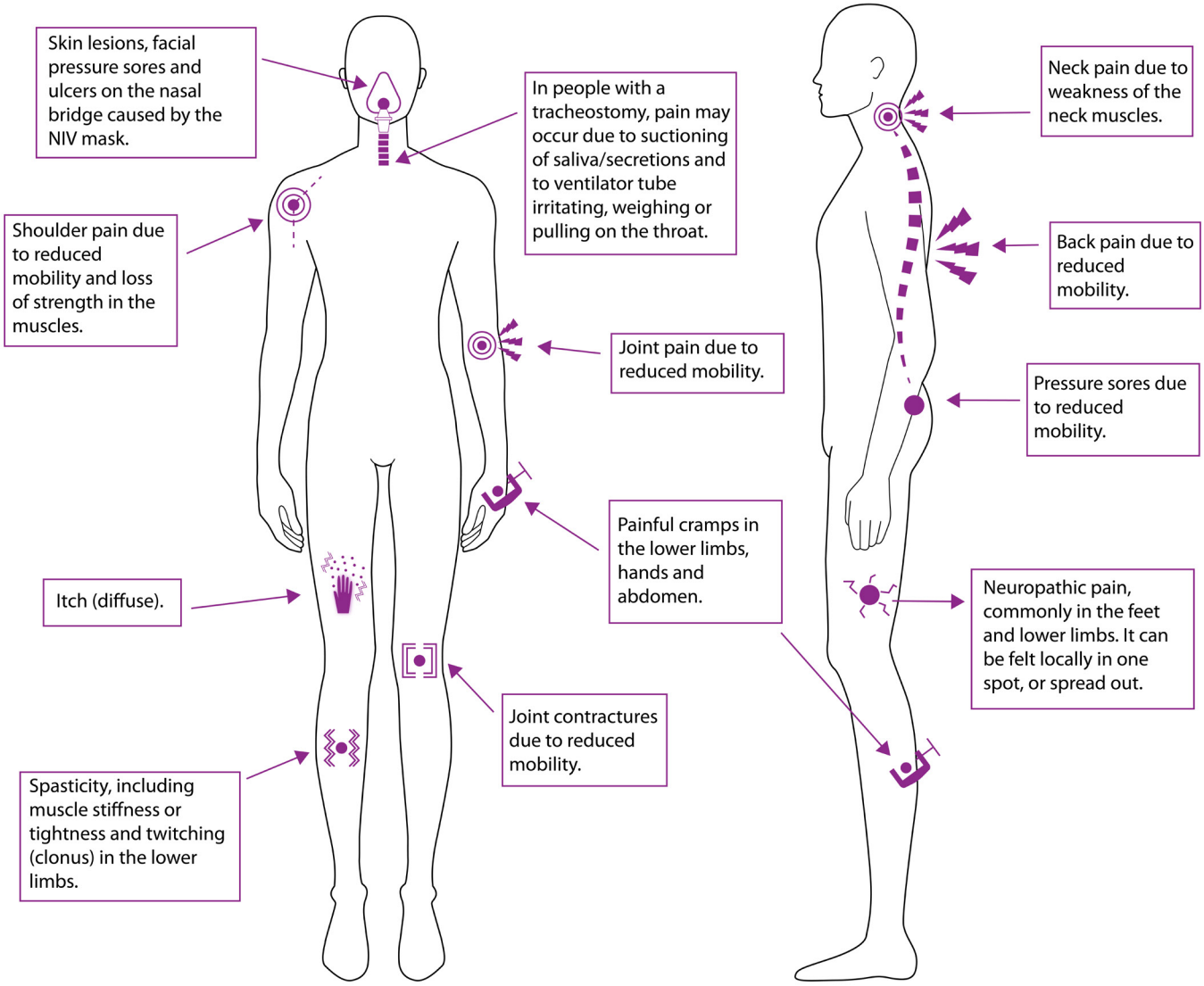
The main causes of pain in MND are spasms (particularly on stretching) and cramps (which are usually short-lived). People with MND might also experience neuropathic pain, which may feel like:[4,6]

- spontaneous burning, tingling or throbbing
- sharp, shooting or stabbing pain
- pain from something that should not hurt eg brushing hair (allodynia)
- pain that feels much worse than expected eg a small bruise feeling like a hard hit (hyperalgesia)
- pain or discomfort that continues after its cause is gone (aftersensation).

Other types of pain may develop as muscles weaken, movement becomes limited, or mechanical ventilation is used for a long time.[5] For example, individuals having invasive ventilation via tracheostomy may experience pain from staying in one position too long. People using non-invasive ventilation (NIV) may develop painful skin lesions on the face due to poorly fitted masks.[4,5]

For this reason, pain should be assessed after starting ventilation, as it may affect whether a person can cope or comply with the treatment.[6] Specialist respiratory teams and ventilation services can help with this.

Some people also report general aching, tenderness, or pain that has no clear cause.[3,4] See the image below to learn more about the different types and locations of pain in MND. People may experience more than one type of pain at the same time.



There is currently no standard tool designed specifically to assess pain in people with MND. The most commonly used tools include:[5,8]

- one-dimensional scales, which measure only pain intensity - examples include the Numerical Rating Scale (NRS) and the Faces Pain Scale (FPS)
- multi-dimensional scales, which evaluate pain and its impact on various aspects of quality of life, including sleep, mood and activities. Examples include the Brief Pain Inventory (BPI) and the McGill Pain Questionnaire (MPQ)
- tools to assess neuropathic components of pain eg the Neuropathic Pain Scale (NPS).

When choosing a tool, consider how MND impacts other functions, such as communication, walking and work abilities. You may need to adjust the assessment method to suit these needs.

Assessing pain in MND can also be difficult because muscle weakness and other motor symptoms are so prominent that pain may be overlooked or under-reported. During appointments, a person may not say they are in pain because they may feel it's not as important as other symptoms. They may believe nothing can be done, or be afraid it might distract professionals from the other symptoms. It is therefore essential to ask about pain, both during the first assessment and at regular follow-up visits.[2,5,6]

Additionally, people with MND who are in pain may report other symptoms, which you can also assess during visits. The most common are:[3,9]

- cold limbs and numbness
- headaches
- sleep problems such as tiredness, drowsiness and nightmares
- constipation, diarrhoea and urinary problems
- sweating.

Managing pain in MND

Pain can be difficult to treat, and there is no single approach that works for everyone. It's important to carefully assess the type of pain someone is experiencing and what might be causing it. This helps create treatment strategies that are tailored to the person's individual needs and reduce the intensity of pain.[4,7] Keep in mind that it may not be possible to remove pain completely.

All members of the multidisciplinary care team should collaborate to assess, manage and review any pain. They should also assess how the person is responding to treatment, whether it is working and whether there are any side effects.[3,6,10]

Medication for pain

Medication relieves pain in nearly a third of people with MND. Traditional analgesics such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) are likely to be beneficial, as are agents which act centrally.[6]

Opioids (eg morphine, buprenorphine or fentanyl patches) may also help with pain relief. Additionally, they could be used for symptomatic treatment of breathlessness (dyspnoea) and coughing.[5] With careful titration, excessive drowsiness and respiratory depression can be avoided.

When prescribing medication, it's essential to consider the person's needs and preferences, as well as any difficulties they may have with swallowing medication.[10] Some people may be reluctant about certain medications, so it's important to investigate and address any concerns.[6]

Anticipatory prescribing is important to help people maintain control. Refer to the British National Formulary (BNF) or Palliative Care Formulary for drug doses.

- For **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.[11]
- For **joint pain**, use simple analgaesia, eg long-acting (NSAIDs).[5] Gastroprotection may be necessary when prescribing NSAIDs.[12]
- For **muscle cramps** consider quinine as a first-line treatment. If quinine is not effective, not tolerated or contraindicated, consider baclofen instead as second-line treatment. If baclofen is not effective, not tolerated or contraindicated, consider tizanidine, dantrolene or gabapentin.[10] Some clinicians also find magnesium or mexiletine to be helpful options before trying baclofen.[4,5]
- For **muscle stiffness, spasticity or increased tone** consider baclofen, tizanidine, dantrolene or gabapentin. If these are not effective, 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, though these have a stronger sedative effect.[4] Injection of botulinum toxin into large muscles may also be effective.[6]

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.[5,8] Close monitoring is essential when prescribing muscle relaxants with opioids, as this combination could cause dangerous drug interactions.[13]

Additionally, check whether the patient is taking any statins, as these medicines can sometimes cause muscle pain and weakness. The GP may review the need for statins, adjust the dose or recommend alternatives if side effects are suspected.[14,15]

Non-pharmacological treatment

Non-pharmacological treatments can also help manage pain caused by immobility, prolonged sitting or stiff muscles.[7]

The NICE guideline on MND (NG42) recommends exercise to help maintain joints' range of movement, prevent contractures, and reduce stiffness and discomfort.[10] Exercise will not reverse existing muscle damage. However, it can help strengthen the muscles that have not yet been affected and offer significant psychological benefits.

Exercise can be either active (where the person moves on their own) or passive (where someone helps move the person's limbs). A physiotherapist can recommend suitable exercises based on:[10]

- the person's level of function, needs, abilities and preferences
- factors such as postural needs and fatigue
- whether family members and/or carers are willing and able to help with exercise.

Physiotherapists can also provide guidance on safe techniques for stretching, moving, or changing positions, to reduce the risk of falls or injuries.[10] Physiotherapists must ensure that anyone assisting the person understands how to carry out these movements correctly. This may include their care workers, carers or other family members.

Other professionals can also recommend ways to manage any causes of pain. These may include massages, orthoses, equipment or advice on posture. Remember that people with MND may need help adjusting their position, and this should be done with great care.

See the table below to learn more.[4,5]

Type of pain or other associated symptoms	Treatment	Professional
Cramps	Regular stretching	Physiotherapist
	Massages	Complementary therapist
	Heat	
Spasms	Active or passive exercise and regular stretching	Physiotherapist
	Warm compresses	
	Changing positions	
Shoulder pain or joint pain	Active or passive exercise to maintain range of motion	Physiotherapist
	Regular stretching	
	Custom-fitted wheelchairs	Wheelchair services
	Massages	Complementary therapist
Joint contractures	Neutral-position splints for hands and ankles	Orthotist

Pain caused by inability to move and change position (eg back pain)	Stretching and passive/active exercise	Physiotherapist
	Changing positions, turning and moving	
	Custom-fitted wheelchairs and canes/ walking sticks to aid mobility	Wheelchair services
	Orthoses	Orthotist
	Profiling bed and special pillows	Occupational therapist
	Equipment to help with daily activities, or alterations to the living space to adapt to reduced movements and avoid strain	
Neck pain	Collars and head supports	Orthotist
Skin lesions and pressure sores	Changing NIV masks – consider that as the disease progresses, the person is likely to lose weight, so the mask might not fit anymore	Respiratory team
	Regularly changing positions and turning	Occupational therapist/ physiotherapist
	Lightweight bed clothing and slide sheets to avoid friction	Occupational therapist
	Bed cradle to relieve the weight of bedclothes	
	Pressure-relieving mattress and cushions	
	Skin care, including managing saliva, which could cause moisture sores. Skin care products and protective tapes eg Siltape over sore areas may also help	Nurse
Constipation and urinary issues*	Passive exercise	Physiotherapist
	Review of food/fluids intake and bowel habits	GP
	Abdominal massages. Laxatives may also help	Dietitian
	Incontinence products	Nurse Continence nurse
Oedema (fluid retention)** – may be caused by sitting in the same position for too long or by other health conditions, which should be treated accordingly[16] Referrals to lymphoedema services may be possible.	Changing positions, adjusting posture and gentle exercise	Physiotherapist
	Compression support stockings and wide, comfortable shoes with a soft sole	Occupational therapist
	Profiling bed and leg lifters	
	Effleurage (light massage) and reflexology	Complementary therapist
	Washing, drying and moisturising feet to avoid infections	Nurse
Sleep disturbances	Profiling bed and special pillows	Occupational therapist
	Review of any breathing issues, which may worsen sleep disturbances and cause anxiety	Respiratory services

* Some people may drink less because they are worried they won't get to the toilet in time (especially if they have mobility issues). However, not drinking enough can irritate their bladder, causing urine infections and making urinary urgency worse. It can also cause constipation.

** Diuretics are rarely helpful to treat oedema as they can promote urinary urgency and electrolyte disturbance.

Learn more with our information for professionals:

Guide - *Occupational therapy for MND*

Guide - *Caring for a person with MND: a guide for care workers*

Information sheet - *Head supports for people with MND*

Information sheet - *Evaluation and management of respiratory symptoms*

Download at **www.mndassociation.org/publications** or contact MND Connect. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

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How we can support you and your team

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals.

Email: mndconnect@mndassociation.org
Phone: 0808 802 6262

MND Association website

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

www.mndassociation.org/professionals

Stay updated on information for professionals:

www.mndassociation.org/educationupdate

X: **mndeducation**

Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, family members and health and social care professionals. Our information can be available in various formats and languages.

www.mndassociation.org/pro-info-finder

www.mndassociation.org/careinfofinder

Education

Our education programme is designed to improve standards of care and quality of life for people with and affected by MND. Opportunities include online webinars and face-to-face equipment training.

www.mndassociation.org/education

Research into MND

We fund and promote research that leads to new understanding and treatments for MND, and brings us closer to a cure.

www.mndassociation.org/research

MND Professionals' Community of Practice

A peer led group of health and social care professionals supporting cross disciplinary learning and the development of good care for people with MND. Join for unique networking and learning events. Being an active member could count towards your professional CPD requirements.

www.mndassociation.org/cop

Financial support

Where statutory provision is not available, we may be able to offer financial support.

www.mndassociation.org/getting-support

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist multidisciplinary care for people with MND.

www.mndassociation.org/care-centres

Local support

We run online and local peer support groups and have trained volunteers and volunteer-led groups offering practical help and support for people with MND, via phone, email or visiting their own home.

www.mndassociation.org/local-support

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan the care and discover more about the cause of the disease.

www.mndregister.ac.uk

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 **www.smartsurvey.co.uk/s/mndprofessionals** or email your comments to **infofeedback@mndassociation.org**

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

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