

P11

Pain in motor neurone disease

Information for health and social care professionals

Motor neurone disease (MND) results from the progressive loss of motor neurones from the brain and spinal cord¹ which leads to weakness, stiffness and loss of muscle mass.

This sheet provides information about how people with MND may experience pain, what can be done to help, and where to find further information and support.

Is MND painful?

Motor neurones do not transmit or modify pain signals, so the disease itself is not inherently painful.² However, pain may be experienced as the ability to move reduces.

Pain can significantly interfere with the quality of life of people with MND, because of its impact on activity levels, mood, sleep, relationships, and general enjoyment of life.^{2,3}

Pain may occur at any stage of MND, including early on, with no relationship between pain intensity and length of time since diagnosis.^{2,4} Because it is usually a result of poor mobility, changes in posture, or reactions to changes in muscle tone, MND pain is more frequent in the limbs.

The most common areas to be affected are legs, arms, shoulders, neck, back, feet, abdomen and hands.² Pain is usually experienced as attacks of pain, with fluctuations or sudden worsening, rather than persistent pain.

People may experience:

- cramps, but these are usually short-lived
- painful spasms, particularly on stretching
- general aching
- sharp or tender sensations
- itchiness.

People with MND who are in pain may also report other symptoms, the most common being:

- sleep problems such as tiredness, drowsiness and nightmares
- constipation, diarrhoea, urinary problems
- itching
- sweating.

A person with MND may not discuss their pain at appointments,² as muscle weakness is often the main concern. It is therefore important to ask about it, both at the initial assessment stage and routinely during follow up visits, as MND is progressive and symptoms change.



"Once he started getting pains across the shoulders and in his arms, and cramps at night, we decided to go along to the GP."

Managing pain in MND

There is no single approach to manage pain in MND, so treatment should be tailored to suit each individual. It is important to be clear that pain can sometimes be difficult to treat and it may not be possible to get rid of pain completely.

Management of pain requires a multidisciplinary approach.⁵

A **physiotherapist** can be very helpful in treating pain in MND.^{2,5} They can suggest exercises and stretches to relieve discomfort or pain from immobility, prolonged sitting, changes in posture, or stiff muscles or joints. These could include passive exercise, or assisted exercise where the therapist or carer helps the person with MND to move their limbs.

While exercise cannot reverse existing muscle damage, it can help maintain or strengthen muscle groups not yet affected. It can also maintain or increase the range of movement in joints and prevent stiffness.

Exercise can provide significant psychological benefits, but great care must be taken to minimise risk of falls or possible injury.



"MND affects my movements, especially my legs...I am still doing a bit of exercise, but if I do too much I get muscle pain, so I just do it gently."

An **occupational therapist** can help make the most of a person's environment, for example by suggesting specialist equipment to help with daily activities, or alterations to the layout of a living space. This can help reduce pain from straining weak muscles.^{2,5}

A **wheelchair therapist** can advise on a suitable chair to help mobility and posture and avoid pressure points. This can help reduce pain from postural weakness.^{2,5}

Correct management of constipation can reduce abdominal pain. The person's **GP**, a **district, community**, or **MND nurse** may be able to prescribe suitable medication.

A **psychologist** can assess emotional needs, or changes in behaviour or thinking and advise on ways to manage feelings associated with pain, such as anxiety and stress. They can also advise carers on manual handling to avoid injuries to both the person with MND and themselves.

Complementary therapies such as massage may be helpful. Heat and rest may also help.⁶

Medication for pain

Pain in MND is generally not neuropathic, in other words it is not a direct result of nerve damage. Medication relieves pain in nearly a third of people with MND. Traditional analgaesics such as paracetamol or non-steroidals, are likely to be beneficial, as are agents which act centrally. Opioids may also help, but may have unwanted side effects.

When prescribing it is important to take into account the person's needs and preferences and whether they may have any difficulty swallowing medication. Refer to British National Formulary (BNF) or Palliative Care Formulary for drug doses.

Anticipatory prescribing is crucial to help the patient maintain control.

- For **joint pain**, use simple analgesia, eg long-acting non-steroidal anti-inflammatory drugs (NSAIDs).⁶
- For **muscle cramps**⁵ consider quinine as a first-line treatment. If quinine is not effective, not tolerated or contraindicated, consider baclofen. Tizanidine, dantrolene or gabapentin may also be considered.
- For **muscle stiffness, spasticity or increased tone**⁵ 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. Some people benefit from use of other benzodiazepines such as diazepam, though these have a stronger sedative effect.

Take care that the dosage of muscle relaxants is carefully adjusted to avoid increased weakness and decreased mobility.⁶ Also check whether the patient is taking a statin and consider this being discontinued, as muscle weakness may be a side effect of statins.⁷

Opiates (morphine, buprenorphine or fentanyl patches) may be used for pain relief and can also be used for symptomatic treatment of dyspnoea and coughing.⁶ With careful titration, excessive drowsiness and respiratory depression can be avoided.

- For **neuropathic pain**⁸ tricyclics or gabapentin or pregabalin may be used.

Skin sensitivity

- Good skin and pressure care is vital.⁹ Someone with MND may be aware when they need to turn or move, but may need help to adjust their position. This must be done with great care.
- Consider equipment for skin sensitivity relief, such as lightweight bed clothing, a bed cradle to relieve the weight of bed clothes, a pressure-relieving mattress and cushions or a slide sheet to avoid friction.
- Advise warm socks for cold feet.

Oedema (fluid retention)

- This may largely be related to restricted activity and posture or to an underlying health condition which should be treated accordingly.¹⁰
- Attention to posture and seating requires regular assessment by an **occupational therapist**.
- Compression support stockings, effleurage (light massage) and reflexology may be beneficial.
- Diuretics are rarely helpful as they can promote urinary urgency and electrolyte disturbance.¹¹
- In some areas, referral to the lymphoedema service may be possible.

Information for people with MND

Information sheet 11E - *Managing pain*

How the MND Association can support you and your team

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

MND Connect

Accredited by the Helplines Standard, MND Connect offers information and support, and signposting to other services and agencies.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Please contact MND Connect if you have any questions about the information in this publication.

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND. Downloads of most of our resources are available from our website at **www.mndassociation.org/publications**

You can also order our publications directly from the MND Connect team.

MND Association website

Access information for health and social care professionals on our website at **www.mndassociation.org/professionals**

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training, such as conferences and masterclasses. Find out more at **www.mndassociation.org/education**

MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or some equipment on loan.

Grants may be given to help with aspects of care or quality of life for people with MND, their carers and younger members of the family. Some referrals need to be made by a health or social care professional.

Call MND Connect on **0808 802 6262**, visit **www.mndassociation.org/getting-support**, or email **support.services@mndassociation.org**

Communication Aids Service

This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **0808 802 6262** or email **communicationaids@mndassociation.org**

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or email **research@mndassociation.org**

Alternatively, for more information visit **www.mndassociation.org/research**

For the latest research news, visit **www.mndresearch.blog**

Our peer-to-peer research and care community blog (ReCCoB) has a number of reporters who write updates on MND-related workshops and events around the world. Subscribe for email alerts at **www.reccob.wordpress.com**

Each year we organise the world's largest clinical and biomedical research conference on MND. It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management. Visit **www.mndassociation.org/symposium**

Local support

Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

MND care centres and networks

We help fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Volunteers

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers. Association visitors are volunteers who provide one-to-one local support to people affected by MND.

Feedback

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our publications, go to **www.surveymonkey.com/s/professionalinformation**

You can request a paper version of the form or provide direct feedback by email: **infofeedback@mndassociation.org**

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

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

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



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