

Pain in motor neurone disease

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.

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 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.

Acknowledgements

This sheet was developed with the kind assistance of:

King's College London and King's College Hospital Motor Nerve Clinic staff, with particular help from Dr Victoria Wallace, Dr Ahmad Al Khleifat and Prof Ammar Al-Chalabi.

This information was produced following their research study into pain and MND, as funded by the National Institute for Health Research, the EU Joint Programme on Neurodegeneration, through the UK Medical Research Council and Economic and Social Research Council, the European Community's Health 7 Framework Programme and the MND Association.

Further thanks to the following, for independent expert review:

Sarah Frankish, MND Co-ordinator, Neuro Physiotherapist, Barts MND Care Centre, London

Timothy L Williams, Newcastle MND Care Centre Director, Consultant Neurologist and Associate Clinical Lecturer in Neurology, Royal Victoria Infirmary, Newcastle upon Tyne

How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

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.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure.

www.mndassociation.org/research

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

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

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

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

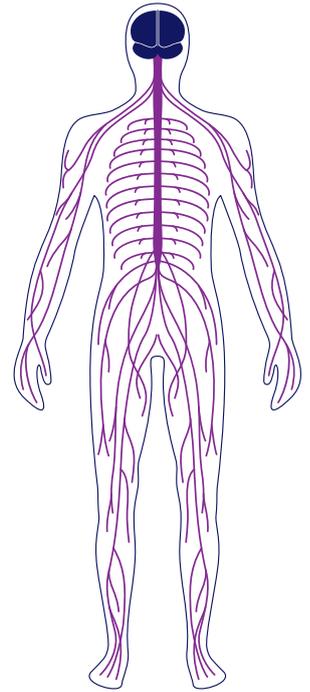
We value your feedback

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

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 sight, hearing or sensation.
- 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 some 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.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

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0808 8026262
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www.mndassociation.org/professionals

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Last revised 03/19
Next review 03/22
Version 1.1
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