



6C

Managing pain

Information for people with or affected by motor neurone disease or Kennedy's disease


If you have motor neurone disease (MND), you may experience pain. While this is not caused by the disease itself, muscle weakness or problems with mobility can cause discomfort. You may have cramps, stiff muscles, and problems from changes to your posture or difficulty moving around. Some people feel more severe pain than others.


If you have Kennedy's disease, with similar symptoms to MND, you may also find this information useful (although Kennedy's disease will usually progress more slowly).

This information sheet explains when pain is likely to happen with MND, what you may feel and how to get help if needed.

The content is split into the following sections:

- 1: Is MND painful?**
- 2: What kind of pain am I likely to feel?**
- 3: What support is available?**
- 4: How do I find out more?**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.

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

1: Is MND painful?

Your motor nerves are affected by MND. They carry messages from your brain, that tell your muscles what to do. When motor nerves are damaged by MND, the messages cannot get through and your muscles no longer move, leading to weakness, stiffness and loss of muscles mass (wasting). This can result in pain.

Your sensory nerves help you to make sense of what is happening to you, including discomfort from injury or illness. As MND does not usually cause damage to sensory nerves, it is not thought to cause direct pain. However, your sensory nerves will carry messages to your brain to warn of any discomfort from MND symptoms.

Pain can happen at any stage, including early on.



"I started to notice the first symptoms. My ankles were weak and aching. I also noticed a limp and the back of my left knee was hurting."

However, you may not experience pain with MND, as it does not affect everyone.

2: What kind of pain am I likely to feel?

As your mobility reduces, you may get stiff joints or find it difficult to move from an uncomfortable position. Changes in posture can also lead to joint or muscle strain.



"For months I didn't associate the pain in my arms to the way I was using my rollator and it was ages before we realised the handle height could be adjusted."

If you have pain or discomfort, the most common areas affected are legs, arms, shoulders, neck, back, feet, abdomen and hands. Depending on your symptoms, you may also experience pain in your tongue or jaw.

You may experience:


- cramp, but this is usually short-lived
- a painful spasm, particularly on stretching
- general aching
- sharp or tender sensations
- itchiness.



"I was having really bad cramps in my legs."


You may also be at risk of injury and resulting pain, if your muscles weaken. For example, you may have a fall, or possibly dislocate a joint, such as in the shoulder. Try not to over exert yourself where this could result in injury.

If you develop problems with your breathing, you may also get headaches.

 For more information about breathing support see:
Information sheets 8A and 8B on breathing and ventilation

These feelings can be tiring and you may find your mood changes if pain persists. It can also affect general activity, relationships and your enjoyment of life.

However, your GP and other members of your healthcare team can support you.

 *"It's important to get any new pain checked out by a health care professional, just in case it's a separate issue to MND."*


3: What support is available?

You may find pain is discussed at appointments with an MND team, for example your healthcare professionals at an MND care centre or network, or other neurological clinic. An MND team are usually familiar with the disease and monitoring of your symptoms is likely to include questions about pain.

However, wider healthcare professionals may not ask about pain, as:

- muscle weakness tends to be the focus, and how it affects daily activities
- they may not realise pain is a problem if they do not have experience of supporting someone with MND.

This means it is important to discuss any pain you have been getting, at healthcare appointments. Your GP, or other specialist professionals in your MND team, can provide support as needed.


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

Can physical therapies help me?

Following an assessment, often with a physiotherapist or neuro physiotherapist, different therapies may be suggested, which could include:


- stretching, which can be helpful to relieve stiffness
- ways to relieve pain from over using one side of the body if you have weakness on the other
- gentle exercise, to relieve discomfort or pain from immobility, prolonged sitting, changes in posture, or stiff muscles and joints
- assisted or passive exercise, where someone helps you to move your 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 range of movement in joints, and relieve stiffness.


 *“My experience is that physical therapy can help. Early on I was given gentle exercises that could be done lying on a bed, mainly stretching and moving limbs. I now find them essential. After a night’s sleep with occasional cramps, I feel very stiff upon waking, but doing my exercises helps.”*

You may find upper or lower limb splints helpful, following assessment by a physiotherapist or occupational therapist. A splint is a strip of rigid material that helps to support, straighten or maintain a limb in position. You may find these assist range of movement and help prevent joint stiffness.

With MND, it is important to minimise risk of falls or possible injury. Exercising to your limit is likely to increase this risk and feel very tiring.

 *“I cannot stress enough the importance of activity pacing – try not to continue tasks until pain or fatigue stop you. Instead, use time as a guide. Relaxation techniques can also help to decrease pain.”*


Your physiotherapist can advise on pacing of activities and help you keep some energy in reserve.


 *“I am still doing a bit of exercise, but if I do too much I get muscle pain, so I just do it gently.”*

If you are a carer, ask the physiotherapist or occupational therapist for advice on manual handling. This is important to know how to best support someone when transferring from one place to another, eg from chair to bed. It can also help you to avoid injury as the carer.

If you have MND, or provide support as a carer, equipment or adaptations can make daily activities safer or more comfortable. It may take time to adjust to using assistive equipment, but it can be of great benefit.

An assessment by an occupational therapist or physiotherapist is recommended before making any equipment purchases, as your needs may change rapidly. Mistakes can be costly and frustrating if equipment is no longer of use when it arrives. Some items may also be available free or on loan from health and social care services.

 *“I use a wheelchair and electric scooter when required. We have also had our bathroom adapted with a shower stool and grab rails.”*

 For more information about equipment and aids see:
Information sheet 11C – *Equipment and wheelchairs*

Ask your GP or other members of your health and social care team about referral to specialists for assessment, such as physiotherapists or occupational therapists.

Complementary therapies, such as acupuncture or aromatherapy, work alongside clinical therapy and medicine.

Some people find complementary therapies helpful to ease pain or for stress relief.



"I found massages of my head and back by my therapist helpful. I think maybe it relaxes my body, taking some stiffness away for a day or two."

If you are receiving support from a palliative care team or hospice, they often provide complementary therapies to patients and close family members. Again, ask your GP or MND team about referral to registered practitioners of complementary therapies, or to palliative or hospice care. There may be a range of outpatient services that can help.



"They have volunteers at the hospice I visit, that can do massages and acupuncture."



For more information see:
Information sheet 6B – *Complementary therapies*

Can medication help me?

Medication can relieve some types of pain. For example:

- cramps or spasms can be treated with medication, such as muscle relaxants
- traditional over-the-counter (OTC) painkillers, such as paracetamol or ibuprofen, may be useful in some situations
- sometimes a specific area of the body needs treatment, for example, with a steroid injection or painkilling cream (ask your GP or MND team).

You may be offered one or more treatments, depending on the cause of your pain.



"After having sleepless nights, from needing to turn frequently due to pain in my hips, I have been prescribed medication which works well."

Always seek advice from your GP or specialist before using any kind of pain relief, whether by home remedy, an over-the-counter product or regular medication.

Who can help me and how?

Following a diagnosis of MND, a wide range of healthcare professionals are likely to be involved in your care. This support may be provided in the community, or at specialist neurological clinics, MND care centres or networks.

Many of these professionals can help if you feel pain.

They are likely to ask:

- How long have you had the pain?
- Where is it?
- What triggers the pain or makes it worse?
- What, if anything, helps you reduce the pain?

They will then suggest suitable treatment options for you to consider. Treatment will only be given with your consent.



"I suffer from head drop and have neck and shoulder pain. Back pain is also a problem due to poor posture resulting from the head drop, particularly when standing. I use a neck collar which does give some support."

Everyone's illness takes a slightly different course, so assessment with a relevant member of your MND or healthcare team is important. This will help ensure your personal needs are met.



"I learnt visualisation techniques from my therapist, for relaxing. Though sceptical at first, I found them invaluable at the dentist where this helped stop my gagging."

Ask one of the following professionals for help if you have pain:

GP – for symptom management, guidance, medication prescriptions and referral to specialist professionals for particular needs.

Neurologist – for comprehensive assessment and symptom management throughout the course of the disease, usually as part of a wider MND team (which could include the professionals in this list or other specialists as relevant).

Palliative care consultant – for a wide range of services to help maintain or improve quality of life.

District or community nurse – for symptom monitoring (sometimes through home visits), and advice. They may be able to prescribe medication or arrange some types of equipment, such as pressure relief cushions or adjustable powered beds.

Specialist nurse – such as a pain management nurse or MND clinical nurse specialist, for guidance following assessment. They may also be able to prescribe medication.

Physiotherapist or neuro physiotherapist – for assessment of movement and guidance on exercise, including assisted or passive exercise. They can also review your needs as they change, and adapt your exercise programme to suit.

Occupational therapist – for assessment of your surroundings. They can suggest changes to make you more comfortable and less likely to experience pain. Equipment can be costly, but some items may be provided by health or social care services, so it is worth having an assessment before buying anything yourself.

Wheelchair specialist – for assessment of wheelchair needs. A suitable chair can assist both mobility and posture, and help avoid pressure points on skin.

Psychologist – for assessment of any emotional needs, or changes to behaviour and thinking. Their guidance may help you adapt your approach and find ways to help prevent pain.

If you have any questions about who can help with a specific need, ask a member of your MND or healthcare team for guidance.

You can also seek our support at the **MND Association**, including support grants to help you and those close to you, including quality of life grants.

Contact our MND Connect helpline to find out more - see *Further information* at the end of this sheet for contact details.

You may also want to share experience with others affected by MND, through our online forum at: **<https://forum.mndassociation.org>**

Many people find it helpful to chat online with others in similar situations or you can just view the posts there.

4: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Adult social care services (sometimes called social services)

For adult social care contact your local authority through your area telephone directory, or search for local authorities at GOV.UK

Website: **www.gov.uk**
www.nidirect.gov.uk (for Northern Ireland)

The Royal College of Occupational Therapists

Sets the professional standards for occupational therapists. You can search for a registered occupational therapist.

Address: Royal College of Occupational Therapists, 106-114 Borough High Street,
Southwark, London SE1 1LB
Telephone: 020 7357 6480
Email: hello@rcot.co.uk
Website: **www.rcot.co.uk**

Disabled Living Foundation

For impartial advice, information and training on independent living.

Address: Disabled Living Foundation, Unit 1, 34 Chatfield Road, Wandsworth,
London SW11 3SE

Telephone: 0300 999 0004

Email: info@dlf.org.uk

Website: www.dlf.org.uk

GOV.UK

Online government advice on a variety of welfare topics, including support for people with disabilities.

Email: email addresses are provided on the website, related to each enquiry

Website: www.gov.uk

www.nidirect.gov.uk (for Northern Ireland)

Health and Social Care Northern Ireland (NHS Northern Ireland)

Online information for NHS services in Northern Ireland.

Email: through the website contact page

Website: www.hscni.net

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards.

Email: through the website contact page

Website: www.wales.nhs.uk

MND Scotland

MND Scotland provides support and information for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

NHS

Online information for the NHS.

Email: through the website contact page

Website: www.nhs.uk

NHS 111

The NHS online/telephone service in England for urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647 (or 111 if available in your area)

Website: **www.nhsdirect.wales.nhs.uk**

NI Direct

Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page

Website: **www.nidirect.gov.uk**

The Patient Advice and Liaison Service (PALS)

Confidential advice about NHS services, offering help with concerns or complaints.

For England, search for PALS on the NHS website: **www.nhs.uk**

For Northern Ireland, see the Patient and Client Council at:

www.patientclientcouncil.hscni.net

For Wales, refer to your local Community Health Council (CHC):

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

References

References used to support this document are available on request from:

Email: **infofeedback@mndassociation.org**

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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Further information

You may find these information sheets from the MND Association helpful:

3A – *MND care centres and networks*

3D – *Hospice and palliative care*

6A – *Physiotherapy*

6B – *Complementary therapies*

11C – *Equipment and wheelchairs*

11D – *Managing fatigue*

We also provide the following guides and resources:

What you should expect from your care – a compact booklet to carry in a pocket, wallet or purse at appointments, to help guide discussions about care needs.

Living with motor neurone disease – our guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at: **www.mndassociation.org/publications** or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through the website

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at **www.smartsurvey.co.uk/s/infosheets_1-25**

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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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