6C

Managing pain

Information for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease

If you have MND or Kennedy's disease, you may experience pain. While this is not usually caused by the disease itself, your symptoms can cause discomfort. Some people feel more severe pain than others. This information sheet explains when pain is likely to happen and how to get help if needed. The content includes:

1. **Are MND and Kennedy's disease painful?**
2. **What kind of pain might I feel?**
3. **What support is available?**
4. **How do I find out more?**

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This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in Section 5 **How do I find out more?**

1. Are MND and Kennedy's disease painful?

With MND or Kennedy's disease, your motor nerves are affected. They carry messages from your brain, that tell your muscles what to do. As these motor nerves become damaged, messages cannot get through and affected muscles no longer move.

This leads to weakness, stiffness and loss of muscles mass (wasting), which can all cause discomfort and pain.

Your sensory nerves help make sense of what is happening to you, including warning of injury or illness. MND and Kennedy's disease do not usually damage sensory nerves and are not thought to cause direct pain. However, sensory nerves do carry messages to your brain to warn of discomfort from MND symptoms. Pressure on sensory nerves can also cause pain, which may happen if your positioning or posture change.

"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."

Pain can happen at any stage, including early on. However, not everyone with MND or Kennedy's disease feels pain or the same level of pain.

2. What kind of pain might I 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.

> **“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.”**

You may experience:

- cramp, but this is often short-lived
- a painful spasm, particularly on stretching
- general aching
- sharp or tender sensations, or itchiness
- discomfort from constipation, caused by lack of mobility, a change in diet or not drinking enough
- bladder spasms or feeling an urgency to pee.

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.

> See our range of information sheets **8A** and **8B** for breathing support.

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.

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 at healthcare appointments to discuss any pain you have been getting. Your GP or 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 phsyiotherapist, 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 or assisted exercise, to relieve discomfort or pain from immobility, prolonged sitting, changes in posture, or stiff muscles and joints.

Exercise cannot reverse existing muscle damage, but 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 keep a limb in position. These can 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 may 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 can help you avoid injury as the carer and work out how to best support someone. They may need your help to transfer from one place to another, such as from a chair to a bed.

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 really help.

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."

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."**

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 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. A neck collar does give some support.”**

Your symptoms may take a different course to someone else with MND or Kennedy’s disease. Assessment through you healthcare team is important to meet your individual needs.

> **“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 help at the MND Association, including financial support to assist you and those close to you, including help for quality of life. Contact our MND Connect helpline to find out more.

See contact details in section 4: **How do I find out more?**

Share experiences with others affected by MND, through our online forum at: **forum.mndassociation.org** Many people find it helpful to chat online with others in similar situations or you can just view the forum posts.

4. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Adult social care services
Contact adult social care services for a needs assessment or carer's assessment.
Website: search for:
find your local council at **gov.uk** (England and Wales)
health and social care trusts at **nidirect.gov.uk** (Northern Ireland)
find my council at **careinfoscotland.scot** (Scotland)

Disabled Living Foundation
A national charity providing advice and information on daily living aids.
Tel: 0300 999 0004
Email: info@dlf.org.uk
Website: **livingmadeeasy.org.uk**

Government information
Online government information about benefits and support. in.
Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

Living Made Easy
For impartial advice, information and training on independent living.
Telephone: 0300 999 0004
Email: info@dlf.org.uk
Website: **livingmadeeasy.org.uk**

MND Scotland
Care, information and research funding for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

The Royal College of Occupational Therapists
Sets professional standards for occupational therapists, with a search facility.
Tel: 020 3141 4600
Email: hello@rcot.co.uk
Website: **rcot.co.uk**

NHS and UK healthcare
Information about NHS services and healthcare across the UK.
Website: **nhs.uk**

For England
Tel: 111 (for urgent medical advice, available 24/7)
Website: **111.nhs.uk**

For Wales
Tel: 111 (for urgent medical advice, available 24/7)
Website: **111.wales.nhs.uk**

For Scotland
Tel: 111 (for urgent medical advice, available 24/7)
Website: **nhs24.scot**

For Northern Ireland
Tel: Available via individual trusts website contact page
Website: **hscni.net**

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References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback,
Motor Neurone Disease Association,
Francis Crick House
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

2B	Kennedy's disease
3D	Hospice and palliative care
6A	Physiotherapy
6B	Complementary therapies

We also have information on equipment, wheelchairs, and environmental controls.

Booklets

What you should expect from your care
Types of care
Personal care
Caring and MND: quick guide

Large guides

Living with MND
Caring and MND - support for you

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

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

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel:	0808 802 6262

MND Association website and online forum

Website:	**mndassociation.org**
Online forum:	**forum.mndassociation.org**

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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