



6A

Physiotherapy and exercise with MND

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

Motor neurone disease (MND) affects people in different ways, but you may experience difficulties with movement, mobility and posture. If you are living with Kennedy's disease, you may be affected in a similar way and find this information useful.

Physiotherapy helps maintain movement and function when someone is affected by injury, illness or disability. This is achieved through movement and exercise, manual therapy, education and advice. Although physiotherapy can't reverse the effects of MND, or Kennedy's disease, it can help you maintain range of movement and comfort for as long as possible.

This information sheet explains how physiotherapy can help with MND, and how to access this support.

The content is split into the following sections:

- 1: How can physiotherapy and exercise help with MND?**
- 2: How do I access physiotherapy services?**
- 3: What other therapies can I try?**
- 4: How do I find out more?**

With MND, we recommend that you get advice from your GP or qualified physiotherapist before starting any exercise programme.

i 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: How can physiotherapy and exercise help with MND?



"I get spasticity, or stiffening, causing my legs to overstretch which is sometimes beyond my control. I find simple exercises help, as do my physio sessions every fortnight."

MND affects the nerves in the brain and spinal cord that control how muscles work, causing muscle groups to become weak. When it is difficult to move a part of the body, joints can become stiff and muscles may tighten, causing everyday activities to become increasingly difficult and sometimes painful. A qualified physiotherapist or neurological physiotherapist (neuro physiotherapist) can offer guidance and exercises to help.

Once the motor neurones that control a particular muscle have weakened, the muscle cannot be repaired by exercise or anything else. However, exercise can help to keep weakened muscles as strong as possible.

Strengthening healthy muscles that have not yet been affected also helps to compensate for muscles that are no longer working properly. Regular exercise can:

- help maintain muscle elasticity
- improve range of movement for joints
- prevent muscles from shortening and tightening (known as muscle contractures or spasticity).

Exercise can also help to:

- keep you mobile for as long as possible, by preventing muscles and joints from becoming stiff
- maintain maximum range of movement (ROM) of joints and help support posture and balance
- maintain comfort and reduce problems linked to muscle weakness and stiff joints
- maintain circulation through active muscle movement.

With MND, assessment by a physiotherapist is important to ensure exercise routines meet your individual needs.



"The neuro physiotherapist changed my life."

Exercise is mentioned in the National Institute for Health and Care Excellence (NICE) guideline on motor neurone disease. This guideline recommends that your health and social care team considers an appropriate exercise programme for you, as part of your care and support.



For more detail on the guideline, see:
Information sheet 1A – *About the NICE guideline on motor neurone disease*
And our pocket-sized booklet: *What you should expect from your care*

What do physiotherapists do?

Physiotherapists help by:

- giving advice on posture and positioning
- developing an exercise programme suitable for your individual needs and abilities
- advising on different ways to do things (including the use of equipment) to make up for loss of movement and how to conserve energy
- providing guidance on breathing and techniques to help you clear your chest and how to save energy (a respiratory physiotherapist usually helps in this way)
- showing your carer how they can help you with your exercises and advise them of safe movement and handling techniques
- providing advice on managing falls
- suggesting ways to manage fatigue.

The physiotherapist will have an ongoing supportive role and help you to stay as independent and comfortable as possible, as your needs change.

What exercises should I do?

Your physiotherapist will tailor your exercises to your individual needs. Any physiotherapy you receive may be different to someone else with MND, as each individual is affected in different ways. You may have other conditions or injuries, unrelated to MND, that may influence the treatment given.

Each physiotherapist will have a different approach, but with common themes. Programmes are likely to include:

Range of movement (ROM) exercises: to maintain movement in your joints. These exercises are usually done systematically, with the joints of one limb exercised in a particular order before the next limb is exercised and so on. The object is to move each affected joint through its full range of motion to prevent stiffening.

Massage and other hands-on techniques: to increase circulation, reduce pain, aid relaxation, assist muscle tone and reduce stiffening and tightening.

Breathing techniques: to make breathing easier and to help clear your chest.

Exercises: to achieve the best possible movement and posture at any stage of the disease.

These exercises can be split into three categories:

Active exercises: when you are able to make your muscles perform their full movement without help.

Active-assisted exercises: when you cannot fully move through an exercise on your own, and a helper assists with the movement.

Passive exercises and stretches: when you cannot perform any of the movement and a helper guides joints through the movements by supporting and moving your limb.

Although MND will continue to progress and cannot be reversed, access to ROM exercises in the early stages of MND can help to maintain and possibly improve your range of movement, for a period of time.

You will be encouraged to follow your physiotherapy plan as independently as possible. However, in time, less active exercises or exercises with assistance may be needed. These can still help prevent joint stiffness and muscle shortening. Your physio can give guidance to your carer on how to help you, if needed.

How much exercise can I do?

How much exercise you can do with MND may depend on:

- how active you were before being diagnosed
- how quickly your needs are changing.

Seeking support from a physiotherapist will help ensure you get an exercise programme that is suited to your individual needs.

If your symptoms are mild to moderate, engaging in mild to moderate exercise may be helpful. Exercise doesn't need to take place in a gym. With MND, it may mean continuing to dress yourself independently or completing achievable daily tasks.

You are the expert in your own body, so only do as much as you feel able and comfortable to do. Extreme resistance exercises are not advised, as this can lead to muscle weakness and put joints at risk of injury.



"I am not able to manage the exercises I was given as it hurts more to try and do them and is exhausting for me."

No exercise should cause you pain. If you do experience pain, stop the exercise and contact your physiotherapist for advice. It may be that you are not doing the exercise correctly, or your exercise programme may need to change. If the pain continues, get advice from your GP.

What if I feel tired?

There is some evidence to suggest that exercising until you feel a little tired with MND can be positive. However, MND can cause fatigue, which is different to the tiredness we all feel from time to time. Fatigue can be described as a constant, overwhelming tiredness which is not relieved by sleep or rest.

It is essential to understand your limitations, as fatigue can increase weakness and drain your energy, making it harder to carry out your daily routines. This includes avoiding excessive exercise, even if passive. This is particularly important as the disease progresses, when even gentle exercise may cause strain if done incorrectly.

If you find that you get tired doing your exercises, doing them a little at a time throughout the day may help you save energy to do the other things you want to do.

If you experience fatigue, ensure you have plenty of rest between exercises as it takes longer for the body to recover.



For more detail on feeling tired with MND, see:
Information sheet 11D – *Managing fatigue*

How often will I see a physiotherapist?

This is likely to vary depending on your needs and how services are run in your area. However, physiotherapists usually prefer an ongoing supportive role, reviewing your needs regularly. Your needs will change with MND and your programme will need to adapt.

If possible, keeping in touch by telephone or email can be a helpful way for your physiotherapist to answer any of your or your carer's questions.

Where can I have physiotherapy?

Appointments with your physiotherapist may take place in a hospital, GP surgery, a health centre or a local hospice. Some physiotherapists will visit you at home if it is difficult for you to travel.

Is physiotherapy linked to occupational therapy?

Physiotherapy has much in common with occupational therapy and the two often work together to provide support.

Physiotherapists mainly deal with physical injury or disorders that affect muscles, joints and limbs. They provide physical treatment, to help maintain or improve movement. They can prescribe a few medicines and recommend or help you arrange certain pieces of assistive equipment.

Occupational therapists do not prescribe medicine, but support people to remain as independent as possible. They do this through:

- providing equipment for daily living
- adapting the home environment
- informing people of different ways to do everyday activities.

With MND, you are likely to meet both a physiotherapist and an occupational therapist. A co-ordinated approach between them can be helpful, as the combination of physical therapy and environmental support can help to prolong your independence and improve your quality of life. If you have not yet seen an occupational therapist and feel it would be helpful, ask your GP for a referral.

Will I still need assistive equipment if I have physiotherapy?

Although physiotherapy can help you to remain independent for as long as possible, MND is progressive and you are likely to use assistive equipment at some point. You can get equipment through a physiotherapist, occupational therapist, other health and social care professionals or through private purchase.

Assistive devices and equipment can help to prolong or improve:

- independence with daily tasks and routines (eg adapted tools and utensils)
- personal mobility (eg ankle and foot supports, walking frames and wheelchairs)
- comfort and positioning (eg riser recliner chairs and powered adjustable beds)
- physical wellbeing (eg head supports, should you experience muscle weakness in the neck, shoulder, and back muscles).

Ongoing support from your physiotherapist and occupational therapist will ensure that you have the appropriate equipment at any particular stage. They may also refer you to other relevant specialists who can provide assistive equipment, eg an orthotist who can assess and fit a foot support (orthosis).



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

2: How do I access physiotherapy services?

An early referral to a physiotherapist will ensure you have correct advice on mobility, exercise and posture as early as possible.

Once you have been diagnosed with MND, you may be referred to a physiotherapist as part of a general medical assessment. You can also ask to be referred, or in many areas you refer yourself. Physiotherapy services operate differently depending on where you live.

Referrals through a health professional will usually be directed to the relevant area of physiotherapy, for example to a neuro physiotherapist, respiratory physiotherapist or domiciliary physiotherapist (who makes home visits).

Not all physiotherapists will have worked with MND before. The specialist skills and experience of a neuro physiotherapist can provide a more in depth approach to specific movement disorders, such as MND. When being referred, discuss what type of physiotherapist would be best suited to help you.

Referral from your GP

Make an appointment with your GP and ask to be referred to a physiotherapist who has knowledge and experience of working with MND or a neuro physiotherapist.

Referral from your MND care centre or network, or local neurological centre

Many people living with MND are linked to an MND care centre or network, or a local neurological centre. Both offer co-ordinated care to people with MND in a multi-disciplinary team (MDT) setting, where you can receive assessments and treatment from a wide range of health and social care specialists, including referral to specialist physiotherapy services.



For more information, see:
Information sheet 3A – *MND care centres and networks*

Local hospices

Physiotherapy is sometimes available through your local hospice, as part of their palliative care services. You can usually self-refer to a hospice.



For more detail, see:
Information sheet 3D – *Hospice and palliative care*

Self-referral

It is becoming easier to refer yourself for NHS treatment. This includes physiotherapy and a range of other health services. Some regions allow people to bypass their GP and go straight to physiotherapists for NHS treatment. Your GP or local NHS hospital will be able to tell you if you can refer yourself to the service.

Paying privately

If you are paying privately for your treatment, there are a large number of physiotherapists across the UK. Check that your chosen physiotherapist is a neuro physiotherapist or has experience of neurological conditions such as MND, and that they are chartered and registered with the Health and Care Professions Council (HCPC). See *Other organisations* in section 4: *How do I find out more?* for contact details.



"I see a private physiotherapist at home twice a week through personal health budget funding."



For detail on how a personal health budget may enable you to choose the physiotherapy services you access, see:
Information sheet 10F – *Personal health budgets*

Occupational health schemes

Some employers run occupational health schemes for their employees that may include physiotherapy. If you are employed, check to see if a scheme is available and if you are eligible.

Private medical insurance

Private medical insurance schemes often include physiotherapy. If you have private medical cover, check to see if you are eligible.

What happens during the assessment?

It is important that any assessment is carried out by a qualified and registered physiotherapist and that treatment is individual to your needs.

An assessment with a physiotherapist will usually consider:

- your muscle tone and muscle power
- the range of movements that you can do on your own or with assistance
- your balance and posture
- your ability to move around to accomplish daily activities, to assess if there are better solutions
- breathing concerns and fatigue
- safe moving and handling, if your carer is assisting you with mobility.

3: What other therapies can I try?

You may experience twinges, aches, cramps and stiffness, which can be uncomfortable at times. Inactivity or sitting for long periods can make this worse. Your physiotherapist or GP may be able to offer various methods of pain relief, including:

- transcutaneous electrical nerve stimulation (TENS), where a small machine uses electrical pulses to stimulate the body's natural pain defences
- applying heat or ice to the affected area
- pain-relieving medication.

Complementary therapies: Some people with MND find complementary therapies can relieve certain symptoms. A wide range of therapies can be accessed, such as massage, acupuncture and reflexology.



For detail, see:

Information sheet 6B - *Complementary therapies*

Information sheet 6C - *Managing pain*

Water therapy (hydrotherapy): The use of water therapy (known as hydrotherapy), can also provide a supportive environment for exercise, particularly for assisted and passive exercise. Water can have a stress-relieving effect on joints, which may also improve breathing, circulation, digestion and promote a sense of wellbeing.



"Hydrotherapy, acupuncture and massage at my local hospice help me relax and feel a little better."

Hydrotherapy for neurological conditions may not be available in all areas, but it is worth asking your GP and health team if a referral is possible. Your physiotherapist can advise about which therapies and exercise routines would suit your needs.

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, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Chartered Society of Physiotherapy (CSP)

A professional body working to achieve and promote excellence in physiotherapy. They have a search engine for you to find a local physiotherapist.

Address: 14 Bedford Row, London, WC1R 4ED
Telephone: 020 7306 6666
Email: through the website contact page
Website: www.csp.org.uk/public-patient/find-physiotherapist

GOV.UK

Online government advice on a variety of welfare topics for people in England and Wales, including support for disabled people.

Website: www.gov.uk

Health and Care Professions Council (HCPC)

A regulatory body who keep a register of health professionals who meet their standards of practice.

Address: 184-186 Kennington Park Road, London, SE11 4BU
Telephone: 0300 500 6184
Website: www.hcpc-uk.org

Health and Social Care Online (NHS Northern Ireland)

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page
Website: www.hscni.net

Health in Wales

Online 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

Support and information if you are living with 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 111

The NHS telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

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

NHS UK

The main online reference for the NHS.

Website: www.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 Royal College of Occupational Therapists

The professional body for all occupational therapy staff in the United Kingdom with information on how to find an OT.

Address: 106-114 Borough High Street, Southwark, London SE1 1LB
Telephone: 020 3141 4600
Email: hello@rcot.co.uk
Website: www.rcot.co.uk

References

References used to support this information are available on request from:
email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Further information

We provide related information sheets you may find helpful:

1A – *About the NICE guideline on motor neurone disease*

3A – *MND care centres and networks*

6B – *Complementary therapies*

6C – *Managing pain*

8A – *Support for breathing problems*

10F – *Personal health budgets*

11C – *Equipment and wheelchairs*

11D – *Managing fatigue*

You can also refer to our main guides:

Living with motor neurone disease – our main guide about MND and how to manage its impact

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

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

What you should expect from your care – our pocket-sized booklet containing the main points from the NICE guideline on MND. Using this may help lead to better outcomes for treatment and care

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional 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

MND Association, PO Box 246, Northampton NN1 2PR

Telephone: 0808 808 6262

Email: mndconnect@mndassociation.org

MND Association website and online forum

Website: www.mndassociation.org

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

We welcome your views

Your feedback is really important, as it helps us to develop new materials and improve our existing information, for the benefit of people living with MND and those who care for them. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

If you would like to provide feedback on any of our information sheets, you can access an 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, PO Box 246, Northampton NN1 2PR



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