MND Association

6A

Physiotherapy and exercise with MND

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

MND or Kennedy's disease both affect people in different ways, but many experience difficulties with movement, mobility and posture. Physiotherapy cannot reverse the effects, but it can help range of movement, ease comfort and strengthen unaffected muscles. This information sheet explores how physiotherapy can help through exercise, therapy and guidance. The content includes:

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 access hospice and palliative care?**

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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?**

With MND or Kennedy's disease, seek advice from your GP or qualified physiotherapist before starting any exercise or physiotherapy programme.

1. How can physiotherapy and exercise help with MND?

MND affects the nerves in the brain and spinal cord that control how muscles work, causing muscles to become weak. When moving a part of the body gets harder to do, joints can become stiff and muscles may tighten. This makes everyday activities increasingly difficult and sometimes painful.

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 compensate for muscles no longer working properly.

A qualified physiotherapist or neurological physiotherapist (neuro physiotherapist) can offer guidance and exercises to help.

"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."

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 stiffness in muscles and joints, as well as maintaining posture and supporting balance
- ease comfort and reduce problems linked to muscle weakness and stiff joints
- maintain or improve range of movement (ROM) in 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 NICE guideline on motor neurone disease. This guideline, by the National Institute for Health and Care Excellence, recommends that your health and social care team considers an appropriate exercise programme for you, as part of your care and support.

See information sheet: **1A About the NICE guideline on MND**
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 ways to do things to make up for loss of movement, how to conserve energy and which assistive equipment could help
- offering guidance on breathing and techniques to help you clear your chest (a respiratory physiotherapist may be involved)
- showing your carer how they can help you with exercise and safe moving and handling techniques
- giving advice on managing falls
- suggesting ways to manage fatigue.

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

What exercises should I do?

Your physiotherapist will tailor your exercises to suit your needs. Your physiotherapy may not be the same that someone else with MND would receive, as each individual is affected in different ways. You may also have other conditions or injuries, unrelated to MND, that could influence your therapy.

Each physiotherapist will have their own approach, but they follow common themes. Depending on your changing needs, your programme may include:

Range of movement (ROM) exercises
These maintain joint movement, usually by exercising each joint of a limb in a set order, then the joints of the next limb and so on. Moving each affected joint through its full range of motion helps prevent stiffening. Although symptoms continue to progress and cannot be reversed, access to ROM exercises as early as possible can help you maintain and possibly improve your range of movement, for a period of time.

Active exercise
If you can make your muscles perform their full movement on your own, then you can take part in active exercise. This is where you can do a routine without any help.

Assisted exercise
If you cannot fully move through an exercise on your own, you may need someone to help you move. This is known as assisted exercise.

Passive exercise
At first, you will be encouraged to exercise as independently as possible. In time, you may need more help if you can no longer move limbs on your own. With passive exercises and stretches, someone supports and guides your joints through a routine. These movements help prevent joint stiffness and muscles shortening. Your physiotherapist can give guidance to your carer on how to help.

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

Breathing techniques
Using these approaches can make breathing easier and help clear your chest.

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 and gives you most benefit.

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 it does, stop the exercise and contact your physiotherapist for advice. You may need to change the way you're doing the exercise or adapt the exercise programme. 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 and Kennedy's disease 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.

See our booklet: **Personal care** for more on managing fatigue.

Try to understand your own limits, as fatigue can increase weakness and drain energy, making it harder to carry out daily routines. If you experience fatigue, ensure you have plenty of rest between exercises, as it takes longer for the body to recover. Avoid too much exercise, even if passive. As the disease progresses, even gentle exercise may cause strain if done incorrectly.

If you find that you get tired doing your exercises, try different approaches. For example, do them a little at a time, at different points of the day. This may help you save energy to do the other things you want to do.

How often will I see a physiotherapist?

This is likely to vary depending on your needs and how services run in your area. However, physiotherapists usually like to review your needs regularly, as MND progresses and your programme will need to adapt.

If possible, keeping in touch by telephone or email can be helpful, so that your physiotherapist can answer any questions that you or your carer may have.

Where can I have physiotherapy?

Appointments with your physiotherapist may take place in a hospital, GP surgery, health centre or 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 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 helps ensure you have appropriate equipment to meet changing needs.

They may also refer you to other specialists, such as an orthotist for foot support devices (orthosis).

See our resources on equipment, wheelchairs and environmental controls.

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 soon 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 neuro physiotherapist or a physiotherapist who has knowledge and experience of working with MND.

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 multidisciplinary team (MDT). You can receive assessments and treatment from a wide range of health and social care specialists, including specialist physiotherapy.

See our booklet: **Types of care** for more on MND care centres and networks.

Local hospices
Physiotherapy is sometimes available through your local hospice, as part of their palliative care. You can usually self-refer to a hospice or ask your GP or another member of your healthcare team to refer you.

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.

In England, you can choose physiotherapy services with a personal health budget. See information sheet: **10F Personal health budgets**

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

Occupational health schemes
If you are employed, check to see if your employer runs an occupational health scheme that includes physiotherapy and if you qualify.

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

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 with MND or Kennedy's disease. Also check they are chartered and registered with the Health and Care Professions Council (HCPC).

See section 4: **How do I find out more?** for a list of other organisations.

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, muscle power, balance and posture
- the range of movements that you can do on your own or with assistance
- your ability to move around and do daily activities, and if there are easier ways
- breathing concerns and fatigue
- safe moving and handling, if your carer helps you with mobility.

3. What other therapies can I try?

You may experience twinges, aches, cramps and stiffness, which can cause discomfort. Inactivity or sitting for long periods can make this worse. Your GP or physiotherapist may 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.

Water therapy (hydrotherapy): Water therapy (known as hydrotherapy), can provide a supportive environment for exercise, particularly for assisted and passive exercise. Water can have a stress-relieving effect on joints and may also improve breathing, circulation, digestion and sense of wellbeing. Hydrotherapy for neuro conditions may not be available in all areas, but ask your GP and healthcare team if referral is possible.

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

See information sheets: **6B Complementary therapies** and **6C Managing pain.**

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.

Chartered Society of Physiotherapy (CSP)
Help to find a local chartered physiotherapist near you.
Email: through the website contact page
Website: **csp.org.uk/public-patient/find-physiotherapist**

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

Health and Care Professions Council (HCPC)
Includes a register of health professionals who meet the HCPC standards of practice.
Tel: 0300 500 6184
Website: **hcpc-uk.org**

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**

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

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

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

Telephone Find individual trusts in Northern Ireland on website contact page
Website **hscni.net** (For Northern Ireland)

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

The Royal College of Occupational Therapists (RCOT)
Provides resources and information on how to find an OT.
Tel: 020 3141 4600
Email: hello@rcot.co.uk
Website: **rcot.co.uk**

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Heather Preston	Occupational therapist, SP Therapy Services, Bury.
Heather Taylor	Neurological physiotherapist, SP Therapy Services, Bury.

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

1A	About the NICE guideline on motor neurone disease
6B	Complementary therapies
6C	Managing pain
8A	Support for breathing problems
10F	Personal health budgets

See also our information about equipment, wheelchairs and environmental controls.

Booklets

Making the most of life
Personal care
Types of care
Getting around
Caring and MND - quick guide
What you should expect from your care

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

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