



6A

# Physiotherapy

## Information for people with or affected by motor neurone disease

Motor neurone disease (MND) affects people in different ways, but you may experience difficulties with movement, mobility and posture.

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, it can help you to stay mobile and comfortable for as long as possible.

This information sheet explains how physiotherapy can help if you have been diagnosed with MND and how to access this support.

This information sheet includes 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?**

 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.



The MND Association has been certified as a producer of reliable health and social care information.

[www.england.nhs.uk/tis](http://www.england.nhs.uk/tis)

## 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 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 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 your healthy muscles that have not yet been affected also helps to compensate for the muscles that are no longer working properly. Regular exercise can help maintain muscle elasticity, improve range of movement for joints and prevent muscles from shortening.



*"We use physiotherapy to help individuals achieve their maximum functional mobility, to promote independence, opportunity, control and dignity within the limits of their condition."*

Liza Robinson, physiotherapist

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
- maintain comfort and reduce problems associated with 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.



*"One of the frustrations of a diagnosis of a disease like MND is the knowledge that there is currently no cure and that you are powerless to stop its advance. Physiotherapy has helped me feel proactive rather than a helpless victim."*

### What do physiotherapists do?

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



*"I can't thank the physiotherapists enough for maintaining my quality of life over the years."*

Physiotherapists help by:

- giving advice on posture and positioning
- developing an exercise programme suitable for your particular needs and abilities
- advising on different ways to do things to compensate for loss of movement and how to conserve energy, including the use of equipment
- providing guidance on breathing and techniques to help you clear your chest and how to conserve energy
- showing your carer how they might help you with your exercises and advise them of safe movement and handling techniques.

## What exercises should I do?

Your physiotherapist will tailor your exercises to your individual needs. It is important to note that 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, which can 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.

 *“With gentle persuasion and exercise, my husband regained enough range of movement for me to wash under his arms again and dress him pain free.”*

In the early stages of the disease, you may start with simple exercises you can do yourself. However, in time, less active exercises may be needed. These can still help prevent joint stiffness and muscle shortening.

You will be encouraged to do your physiotherapy plan as independently as possible. Sometimes it is not possible for exercises to be performed without assistance and your physiotherapist is likely to want to meet and give guidance to your main carer.

## How much exercise can I do?

 *“The ‘no pain, no gain’ motto made popular in the fitness community doesn’t apply to people with neuromuscular diseases. Your goal should be to maintain functional strength, endurance and independence, and pain won’t help you get there.”*

Mike Haynes, Muscular Dystrophy Association US

Your physiotherapist will advise you on how much exercise to do, depending on your individual needs.

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 be changed. If the pain continues, get advice from your GP.

 *“Prior to becoming ill, I was a wee bit of a gym junkie...I was used to monitoring speeds, endurance, flexibility, muscle tone, weight and the like...Following diagnosis, I found it difficult to exercise when I could see no progress. Now, with my mobility affected, I am able to see the benefits of such limited exercise.”*

With MND, you can easily over-tire yourself, so avoid vigorous exercises and stretches. Extreme resistance exercises are not advised, as this can lead to muscle weakness and make joints susceptible to injury.

It is essential to understand your limitations, as fatigue will only increase weakness and sap your energy, making it harder to carry out your daily routine. This includes avoiding excessive passive exercise. 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, do them a little at a time throughout the day so that you have the energy to do the other things you want to do.

## **How often do I need to see a physiotherapist?**

This is likely to change depending on your needs and will also depend on how services are run in your area. However, a physiotherapist usually prefers 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 questions you or your carer may have.

## **Where can I receive 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 particularly difficult for you to travel.

## **Is physiotherapy linked to occupational therapy?**

Physiotherapy has much in common with occupational therapy and the two disciplines 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.

An occupational therapist does not prescribe medicine, but supports people to remain as independent as possible through equipment for daily living, adapting the home environment and informing people of different ways to do everyday activities.

With MND, you are likely to meet both a physiotherapist and an occupational therapist. A coordinated approach between them can be beneficial, 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 need to use assistive equipment at some point.

Equipment can be sourced through a physiotherapist, an 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 from ankle and foot supports, to 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 can make your own referral. It is important to note that physiotherapy services operate differently depending on where you live.

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

Not all physiotherapists will have worked with MND before. The specialist skills and experience of a neurological physiotherapist can provide a more in depth approach to specific movement disorders, as with 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.

### **Referral from your MND care centre or local neurological centre**

Many people living with MND are linked to an MND care centre 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.

### **Self-referral**

It is becoming easier to refer yourself for NHS treatment. This includes physiotherapy and a whole 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 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.

### **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 tailored 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
- local application of heat or ice
- 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 more information see:

Information sheet 6B - *Complementary therapies*



*"The physiotherapist suggested acupuncture to relieve stiffness in my neck. I was sceptical at first but it made an amazing difference"*

**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. The buoyancy of water can have a stress-relieving effect on joints, which may also improve breathing, circulation, digestion and promote a sense of wellbeing.



*"Utilising the buoyancy of the human body in water, the participant can be handled easily by the physiotherapist. Away from the pull of gravity the individual can achieve a feeling of weightlessness and freedom not accessible on dry land. As a result they may be able to move weak or painful limbs that are too difficult on land."*

Heather Taylor, physiotherapist

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.

**Music therapy:** Some people with MND have reported that music therapy has been a calming process, helping to reduce stress levels. Music therapy can also enable emotional and creative expression. Again, ask your GP, physiotherapist or health team if any qualified therapists exist in your region and if a referral is possible. If not, they may be able to advise on how best to search for this type of therapy should you wish to make enquiries further afield.

## 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).

#### The British Association and 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 7357 6480  
Email: [reception@cot.co.uk](mailto:reception@cot.co.uk)  
Website: [www.cot.co.uk](http://www.cot.co.uk)

#### 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: [enquiries@csp.org.uk](mailto:enquiries@csp.org.uk)  
Website: [www.csp.org.uk](http://www.csp.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](http://www.gov.uk)  
[www.nidirect.gov.uk](http://www.nidirect.gov.uk) (*Northern Ireland*)

#### Health and Care Professions Council (HCPC)

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

Address: Park House, 184 Kennington Park Road, London, SE11 4BU  
Telephone: 0845 300 4472  
Email: [publications@hpc-uk.org](mailto:publications@hpc-uk.org) (for enquiries about published information)  
Website: [www.hpc-uk.org](http://www.hpc-uk.org)

#### Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards. This is an online information service only.

Email: through the website contact page  
Website: [www.wales.nhs.uk](http://www.wales.nhs.uk)

### **MND Scotland**

They have published a leaflet called Getting the Best from Physiotherapy.

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

Telephone: 0141 332 3903

Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)

Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

### **NHS Choices**

The main online reference for the NHS, including information on continuing healthcare.

Address: Customer Service, Richmond House, 79 Whitehall, London SW1A 2NL

Email: through the website contact page

Website: [www.nhs.uk](http://www.nhs.uk)

### **NHS 111**

The NHS online/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

### **NHS Direct Wales**

Health advice and information service for Wales.

Telephone: 0845 4647

Website: [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

### **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](http://www.hscni.net)

### **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](http://www.nidirect.gov.uk)

## **References**

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

3A – *MND care centres and networks*

6B – *Complementary therapies*

7A – *Swallowing difficulties*

8A – *Support for breathing problems*

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

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

[www.mndassociation.org/publications](http://www.mndassociation.org/publications) or order in print from the MND Connect team, who can provide additional information and support:



### **MND Connect**

MND Association, PO Box 246, Northampton NN1 2PR

Telephone: 0808 808 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### **MND Association website and online forum**

Website: [www.mndassociation.org](http://www.mndassociation.org)

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

## **We welcome your views**

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: [www.surveymonkey.com/s/infosheets\\_1-25](http://www.surveymonkey.com/s/infosheets_1-25)

You can request a paper version of the form or provide direct feedback by email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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