



11D

Managing fatigue

Information for people with or affected by motor neurone disease

We all feel tired at times, but with MND you may experience extreme tiredness, known as fatigue. This can happen often and it may become difficult to manage daily routines.

This information sheet explains how to identify the signs of fatigue and suggests ways to reduce its impact.

The content is split into the following sections:

- 1: **What is fatigue?**
- 2: **What causes fatigue?**
- 3: **How can I manage fatigue?**
- 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: What is fatigue?

Fatigue is one of the most common symptoms of MND. It causes you to feel more exhausted than you would expect, either following an activity or even while resting. This can make daily life very challenging.

Fatigue varies from person to person. Certain activities can be exhausting for some people and not so much for others. It can be experienced mentally and physically, and the way it affects you can change from week to week or even day to day. It can happen gradually, or you may lose your energy suddenly.

Signs of fatigue include:

- feeling exhausted most of the time, even after minor activity
- feeling tired even though you have had a good night's sleep
- a feeling of heaviness in your body or limbs
- feeling too tired to carry out normal daily activities
- difficulty concentrating
- drowsiness or feeling 'foggy'
- sleepiness.

It may not be possible to stop this happening completely, but there are ways to reduce fatigue and its impact on your life. Ask your health and social care team for advice, as support is available.



For more about the causes of fatigue and practical help, see section 2: What causes fatigue? and section 3: How can I manage fatigue?

2: What causes fatigue?

MND affects your muscles, causing them to become weaker and lose mass (known as atrophy or wasting). This can make you feel fatigued, as activities will feel more tiring and require more effort than before.

You may also experience fatigue due to:

- sleep problems
- breathing difficulties
- weight loss
- medications
- low mood or depression.

Will rest help?

Ensuring you get plenty of rest can help you manage fatigue. Plan each day to incorporate regular rest breaks if possible. Plan a day of rest before and after a busy time, such as a family event.

Although chatting to friends, watching TV or reading a book may feel relaxing, try to do as little as possible while resting to get the full benefit. This means both physical and mental rest. Some people find relaxation techniques helpful with this. Ask your GP or a member of your health and social care team.

How can exercise help?

While exercise cannot reverse damage to muscle groups weakened by MND, it can help to:

- strengthen muscles that have not yet been affected
- keep the muscles that have been affected by MND supple
- reduce tightening of muscles affected by MND (which causes stiffness, known as spasticity)
- improve general wellbeing, as it may help to encourage a good sleep pattern.

Get advice from a qualified physiotherapist with experience of MND, about exercise that will be suitable for you. They will assess your individual needs and look at a suitable level of exercise. Your physiotherapist can also advise on different ways to do things, to conserve energy and compensate for loss of movement.



For more information about physiotherapy with MND, see:
Information sheet 6A – *Physiotherapy*

However, if access to a physiotherapist is not available, particularly early in the disease when disability is mild, this should not prevent you from doing low impact exercise such as swimming, walking and cycling.

With MND, it is important to avoid additional fatigue when exercising, and minimise risk of falls or possible injury. Exercising to your limit is likely to make fatigue worse, and your physiotherapist may recommend a more cautious approach to keep some energy in reserve.

How can equipment help?

Finding ways to do tasks more easily can save energy. A wide range of assistive equipment is available to help with:

- walking and mobility
- getting around within your home, socially etc
- personal care – such as eating and drinking, washing and dressing, bathing and showering, using the toilet
- communication – talking to people face to face or on the phone, and using social media.



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

It is recommended you have an assessment of your equipment needs by an occupational therapist. Equipment can be costly and not all items are suitable for everyone. Some equipment can be provided for you by statutory services, so an assessment may be worthwhile before buying anything yourself.

As MND progresses, your occupational therapist should be able to advise about changes to equipment and help you plan for possible future needs. With fatigue, equipment and aids may not be the only answers. You may be advised to think about home adaptations or installations of larger equipment, such as a through floor lift.

For larger pieces of equipment or home adaptations, a Disabled Facilities Grant (DFG) may be available, if you are assessed as eligible. You can apply for this grant from your local authority or, in Northern Ireland, your local health and social care trust. As a DFG can take a long time to be agreed, some people fund the work themselves or seek funding from charities to get the work done quickly.



For more information about Disabled Facilities Grants, see:
Information sheet 10C – *Disabled Facilities Grants*

If you are experiencing difficulty with accessing the equipment you need, or you are not eligible for statutory provision, you can seek support from The MND Association.

MND Connect helpline: Our helpline team can offer information and support on all aspects of MND. They can also guide you to our own services and other organisations, as appropriate. MND Connect is available Monday to Friday between 9am to 5pm and 7pm to 10:30pm. Call 0808 802 6262 or email mndconnect@mndassociation.org

Equipment loan services: We loan a limited range of equipment where statutory funding is not available or when there is a delay. Requests for equipment loan need to be made by a relevant health or social care professional following assessment of your needs. Contact our Support Services team on 0808 802 6262, or email support.services@mndassociation.org

Wheelchair enquiries: Our Wheelchair Co-ordinator develops links with external wheelchair services and helps progress reported problems with delays, service or provision. The co-ordinator also processes applications for support grants to fund wheelchair top-ups for non-standard features or additional equipment. For further information, contact: wheelchairs@mndassociation.org or call MND Connect.

Communication aids enquiries: We may be able to loan equipment to you, or offer a limited amount of financial support towards communication aids where statutory services cannot supply. This can only be given following an assessment by your speech and language therapist. If you would like more information, email communicationaids@mndassociation.org or call MND Connect on 0808 802 6262.

Financial grants for you and those close to you: We also offer a range of support grants to help you and those close to you. Our care grants may be able to help you with quality of life or fund equipment if not available from adult social care services or the NHS (or if there are excessive delays in accessing the equipment). You will need to be assessed by a health and social care professional if being funded for assistive equipment. Contact our Support Services team on 0808 802 6262, or email support.services@mndassociation.org

What if I'm struggling to sleep?

If you haven't slept well, you may feel unrefreshed, experience headaches and feel sleepy during the day.

With MND, problems with sleep may be due to:

- reduced mobility, making it difficult to turn and find a comfortable position
- muscle cramps
- swallowing problems causing drooling and possible coughing
- disturbances to your breathing
- anxiety.

Discuss sleeping problems with your neurologist in order to clarify which of the above factors is the cause of disturbed sleep, and with your health and social care team, as support is available. This will vary, depending on the cause of your sleep problems. For example, an adjustable bed may help with getting in and out, and positioning for comfort, when managing fatigue.

If physical discomfort disturbs your sleep, support such as equipment, exercises and advice on posture can help you feel more comfortable. Medication may help if you have stiff, tight muscles or cramps.

If you are having difficulties sleeping due to anxiety, see your GP or palliative care team for guidance. See heading *What if I'm depressed?* later in this section.

How can breathing support help?

If your breathing has been weakened by MND, you are not able to draw as much air into your lungs. This can leave you feeling tired and affect the quality of your sleep.

Contact your neurologist or health and social care team for advice. Ask for referral to your local specialist respiratory team, who can assess your breathing and discuss options for treatment and care. This may include non-invasive ventilation (NIV) which uses a machine to assist your breathing, by helping with the flow of natural air.



For more information about breathing and ventilation, see:
Information sheets 8A to 8D

How can weight loss affect fatigue?

Eating and drinking may become tiring if you have weakened arms, and your posture is affected by MND. Your occupational therapist can advise you on equipment to support your positioning as well as equipment to make mealtimes easier.

With MND, muscles in your throat and mouth may become weak, slow or uncoordinated. This can affect your ability to chew and swallow, leading to weight loss and lack of energy. Dehydration can also cause fatigue.

Ask your health and social care team for a referral to a speech and language therapist (SLT) and a dietitian, who can advise on how to get the nourishment you need.




For more information, see:
Information sheet 7A – *Swallowing difficulties*

You may decide to have a feeding tube. This is a way of receiving liquid feed, fluids and medication straight into your stomach, through a tube in your abdomen.

While tube feeding can replace eating and drinking if required, it can also be used simply to top-up meals. This means you can still enjoy food and drink by mouth, for as long as you wish to or feel safe to do so.

Tube feeding can help you maintain weight. It can also save energy for both yourself and your carer if you find it takes a long time to finish meals.


It is helpful to find out about this option as early as possible. Ask your dietitian or another relevant member of your health and social care team for more information. It may become more difficult to introduce tube feeding as your symptoms increase.

 For more details, see:
Information sheet 7B – *Tube feeding*

Is my medication causing fatigue?


Some medications prescribed to manage symptoms of MND, may cause fatigue in some people. This includes riluzole, and certain medications for saliva problems, muscle cramps and pain.

Ask your health and social care team to review your medication if you are experiencing extreme tiredness, as adjusting the doses may help.

 For more information about riluzole see:
Information sheet 5A – *Riluzole*

What if I'm depressed?

Living with MND can be emotionally challenging. Low moods, anxiety and depression can leave you feeling very tired, but support is available.

 For information about coping with the emotional impact of MND, see our guides:
Emotional and psychological support and
Changes to thinking and behaviour with MND

If you feel very low and these feelings do not pass, it could be a sign that you are depressed. Ask your neurologist or GP for guidance if you experience:

- feeling persistently sad or anxious
- feeling worthless
- loss of interest and pleasure in things.

Our MND Connect helpline can offer you support and information on all aspects of MND. See *Further information* in section 4: *How do I find out more?* For contact details.

3: How can I manage fatigue?

Members of your local health and social care team should be able to advise how to carry out activities more efficiently to conserve energy.

The experience of fatigue is different for everyone, and you are likely to develop some of your own solutions. Sharing ideas with other people affected by MND can be helpful. Our online forum provides a safe place for you to communicate with other people affected by MND. Visit the forum at: <https://forum.mndassociation.org>

You may find the following suggestions helpful as a starting point:

Budget your energy: It can help to think about energy like a 'bank account'. If you 'overspend' on energy one day, you may feel extremely tired the next. Plan what you really want or need to do first. Delay or get help with other tasks as needed.



"I think of fatigue in terms of my batteries running low and needing to recharge them."

Be flexible: Don't try and force yourself to finish a task if you need to rest. You will feel better in the long run if you take your time. Plan ahead, and spread activities over the course of a week rather than trying to fit everything into one day. Stop an activity before you become over-tired.

Prioritise: Prioritising activities can help save energy. Think about which are most important, which can wait, where you may need help and which tasks can be handed over to someone else entirely.



"It's important to emphasise – pick activities you enjoy against activities you feel obliged to take part in."

Get help: Ask your family, friends or carers to help with the things you find tiring or hard to do. You may also want to consider accessing external support. If you are not currently receiving a care package, contact your local adult social care services or, in Northern Ireland, your health and social care trust for a needs assessment.

Consider your body temperature: Excessive heat can leave you feeling tired, while coldness can leave muscles feeling stiff and tight. Layers of loose, lightweight clothing provide excellent insulation, but can be added or removed as needed.

Keep a fatigue log: Record how tired you feel after each activity over a period of time. This may help you find patterns and identify which activities tend to drain your energy. Keeping track of your sleep patterns can also be useful.

How can I adapt my activities to save energy?

There are many ways of adapting everyday tasks to use less energy. A member of your health and social care team should be able to advise you on how best to reduce the amount of energy you spend on day-to-day tasks.

Some ideas that may help you save energy include:

Around the home:

- keep essential items close to hand, so you don't waste energy looking for things
- sit rather than stand whenever possible, eg when washing up, ironing or preparing food
- make meals in batches and freeze extra portions for another day
- let dishes soak before washing, and let them dry on a draining board rather than drying them with a cloth
- place chairs at convenient points around your house, so you can rest wherever you need to
- push, slide or roll objects rather than lifting them
- ask for help with chores, such as cleaning or shopping
- have groceries delivered.

Personal care:

- dry off after a shower by wearing a towelling robe to absorb the water
- use an electric toothbrush or razor instead of a manual one
- wear clothing that is easy to put on and take off
- rest before and after a bath or shower.

Your health and social care team will be able to suggest more ways to manage fatigue.

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 College of Occupational Therapists

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

Telephone: 020 7357 6480
Email: through the website contact page
Website: **www.cot.co.uk**

Disabled Living Foundation

Provide impartial advice, information and training on independent living.

Address: 4th Floor, Jessica House, Red Lion Square, 1
91 Wandsworth High Street,
London SW18 4LS

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 (Northern Ireland)

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 Choices

The main online reference 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

Website: **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**

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**

Rica

Rica carries out research and publishes information to enable disabled and older people to live more independently.

Address: G03, The Wenlock, 50-52 Wharf Road, London N1 7EU

Telephone: 020 7427 2460

Email: mail@rica.org.uk

Website: www.rica.org.uk

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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Professor Kevin Talbot, Head of the Division of Clinical Neurology, University of Oxford

Further information

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

5A – *Riluzole*

6A – *Physiotherapy*

7A – *Swallowing difficulties*

7B – *Tube feeding*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

11C – *Equipment and wheelchairs*

We also provide the following guides:

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

End of Life: a guide for people with motor neurone disease – includes Information to help people plan ahead for end of life.

We also provide the following tools that you may find useful:

Understanding my needs – a tool to help health and social care professionals to understand how MND affects you

MND alert card – a card to carry in your pocket, purse or wallet that states you have MND and provides details of your emergency contacts

MND checklist – a tool to help you manage your condition and think ahead

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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