



Motor Neurone Disease: how to find out more

**Guidance for people with motor neurone disease (MND),
their families and carers**





In need of support?

If you or someone close to you has been diagnosed with motor neurone disease, you may be looking for guidance. We are here to help at the MND Association, with understanding, information and financial support.

Use this leaflet to find:

- basic facts about MND
- contact details for our MND Connect helpline
- how our services can help you
- ways to access our information resources
- useful links to explore our website.





What is MND?

MND affects the nerves in the brain and spinal cord. This means messages gradually stop reaching muscles, which leads to weakness and wasting.

It affects more than 5,000 adults in the UK at any one time and six people per day are diagnosed with MND.

Adults of all age can get MND but most of those affected are between 50 and 70 years of age.

A small number of people with MND have a family history of the condition, known as inherited MND.



About 1 in 10 of those diagnosed with MND are thought to have the inherited form.

MND is a life-shortening disease. It is unpredictable and no two people will have exactly the same experience.

This is because symptoms and the speed at which symptoms progress can vary.

How will MND affect me?

MND can affect how you walk, talk, eat, drink and breathe. In some cases it can also affect the way you think and behave. However, not all symptoms happen to everyone and it is unlikely they will all develop at the same time, or in any set order.

There is no way to stop MND yet but research is ongoing and much can be done to manage symptoms. If you have MND, support can help you achieve the best possible quality of life.

Seek out guidance as soon as you can after diagnosis. This helps you get the most benefit from available care support, clinical care, benefits and entitlements.

The earlier you explore what is available, the more support can be given to control symptoms and maintain quality of life as far as possible.

If you are close to someone with MND, you may be supporting them. As care needs increase over time, you may also need help in your caring role.

Who do I contact for help?

Our MND Connect helpline can help you with guidance, information or how to access our financial support.

The team can explain how our services work and help you find other specialist services you may be entitled to.

Contact MND Connect:

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

See more about our services on the next page.



How can you help me?

Every day we support people affected by MND, 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 support, information and signposting to people with MND, Kennedy's disease, carers, family and professionals. Find out more and opening times at mndassociation.org/mndconnect

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org



Support services

Find out about our financial support and services at mndassociation.org/our-services

For help to identify claims, find details about our Benefits Advice Service at:

mndassociation.org/benefitsadvice



Local and regional support

Find out about our regional staff, volunteers, branches and groups at

mndassociation.org/local-support



Other links

Online forum: forum.mndassociation.org
Website: mndassociation.org
Research: mndassociation.org/research
Campaigning: mndassociation.org/campaigning
Fundraising: mndassociation.org/fundraising
Volunteering: mndassociation.org/volunteering



Our information

We offer a wide range of accredited resources about MND and Kennedy's disease, including information sheets, booklets, guides and more.

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.



Our health and social care information is evidenced, user tested and reviewed by experts. See: piftick.org.uk

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people affected by
motor neurone disease.**

**Because with MND,
every day matters.**

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Registered Charity no. 294354

Revised: January 2026

Next review: January 2029

Version: 1

