MND Association | For professionals

Our support for MND professionals

About Motor Neurone Disease

Today, six people

will be told they have MND and six people will die from the disease. There is no cure.

MND is a fatal, rapidly progressing disease.

It affects the nerves in the brain and spinal cord that control muscles.

A third of people will die within a year of diagnosis.

More than half will die within two years.

People may lose movement, speech, swallowing and breathing.

This affects quality of life for them and those around them.

MND doesn't discriminate.

It affects people from all backgrounds and at all ages.

People with MND may experience changes in thinking and behaviour.

Some develop frontotemporal dementia, with more severe changes.

MND affects everyone differently.

Symptoms progress at different speeds and a different order for everyone.

Contents

Section 1: Support and information

Section 2: Practical support

Section 3: Local support

Introduction

Motor neurone disease (MND) is a progressive, fatal disease that attacks the motor neurones, or nerves, in the brain and spinal cord. About two people in every 100,000 of the general population will develop MND each year.

MND can affect how people walk, talk, eat, drink, breathe and think. Not all symptoms affect everyone, and it is unlikely they will all develop at the same time or in any specific order. There is no cure for MND, but symptoms can be managed to help improve quality of life.

About this guide

The MND Association supports health and social care professionals to provide the best possible care for people living with MND or Kennedy's disease, their carers and families.

We do this in a number of ways which are described in this guide.

Section 1: Support and information includes our resources and services to learn more about MND care and help you in your practice.

Section 2: Practical support describes a number of services that offer practical support for people with or affected by MND or Kennedy's disease. As a health and social care professional, you may need to help people in your care access these services by referring them or providing evidence on their behalf.

Section 3: Local support describes how the Association can provide local support to both professionals and people with or affected by MND or Kennedy's disease.

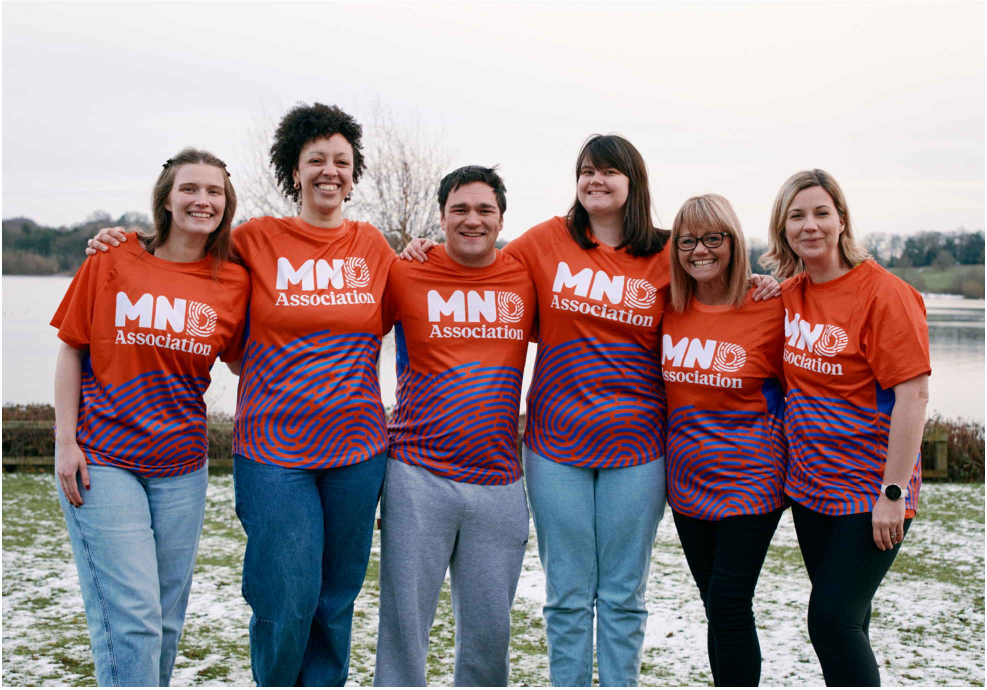
MND Association membership

Join us now and help fight MND. Membership fees are discretionary.

As a member, you will receive:

- a welcome pack with a pin badge and a membership card
- quarterly Thumb print magazine
- connection to your local branch or group
- the opportunity to attend and vote in the annual general meeting
- invitations to conferences and events.

If you have any questions about memberships, please contact the Supporter Care team. Email membership@mndassociation.org or call 01604 611860.



1

Support and information

MND Connect Helpline

Our helpline offers information and support on all aspects of MND or Kennedy's disease, including:

- information about MND or Kennedy's disease symptoms
- emotional and practical support
- social, practical and financial information
- information about local support
- information about MND Association services and support
- signposting to other appropriate services.

MND Connect is available Monday to Friday, between 9am–4pm. Calls are free from landlines and mobile phones within the UK. The helpline offers support to people with MND or Kennedy's disease, carers, family members and anyone else affected by these conditions, including health and social care professionals. Contact the team by emailing mndconnect@mndassociation.org or call 0808 802 6262.

The MND Association website

Our website has a vast amount of useful information for health and social care professionals on the management of MND, education events and more. The following links may be useful:

- **mndassociation.org/professionals** – our main hub for health and social care professionals
- **mndassociation.org/support-and-information** – our hub page with details of the information and support we offer.

The following links may be useful to share with people with MND:

- **mndassociation.org/CYP** – for children and young people
- **mndassociation.org/carers** – for unpaid/family carers
- **mndassociation.org/bereavement** – for people experiencing a bereavement due to MND
- **mndassociation.org/kennedys** – for people affected by Kennedy's disease.

Our social media are also a helpful way to learn the latest news about our work and MND care:

- X: **mndeducation**
- Bluesky: **mndeducation.bsky.social**

We also send out a monthly newsletter with information on MND relevant to health and social care professionals. This includes updates on our services, education events and opportunities to participate in research projects or work with us.
You can sign up on **mndassociation.org/educationupdate**.

Finally, we host a private group on Facebook for health and social care professionals. This group is a space where you can exchange ideas and support with colleagues.

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND or Kennedy's disease. Our publications range from comprehensive guides to practical care pathways. All of them are regularly reviewed with the help of expert MND professionals.

We also have a wide range of resources for people living with and affected by MND, including carers, children and young people. Resources include guides, information sheets, forms to bring to clinical appointments, and much more. Some of these are also available in different languages and formats, upon request.

Our care information is accredited by PIF Tick, the only UK quality mark for trustworthy health information.

Professionals can use this information themselves to open conversations with the people in their care, or share it with people with MND, their family and carers, to help them understand MND symptoms and the support available. We also have a number of decision aids to help people make care decisions.

All our information can be found online on our website, or ordered. See page 19 to learn more.

We have designed two tools to help people easily find the specific information they are looking for on our website:

- **Care information finder** – allows you to browse information for people with and affected by MND by selecting a topic of interest. It includes a function to email the results of the search. **mndassociation.org/careinfofinder**.
- **Professional information finder** – allows to search information according to a topic or a specific profession. The results include both information for professionals and for people with and affected by MND. **mndassociation.org/pro-info-finder**.

Education

Our education programme is designed to support professionals to improve standards of care and quality of life for people with and affected by MND.

All events are led by experts and aim to supplement your existing training with MND-specific knowledge and skills to apply directly to your practice. Every year, we cover a wide range of topics in which professionals themselves indicate they are interested, or in which there have been new developments.

Opportunities include webinars, in-person and online workshops, masterclasses and online courses.
Find out more at **mndassociation.org/education**.

Community of Practice

The MND Professionals' Community of Practice is a peer led group of health and social care professionals supporting the development of good care for people with MND. It encourages cross disciplinary learning, collaboration and the exchange of knowledge and resources.

Members also have access to exclusive events, where you can network with fellow professionals, share your experience and present your ideas or projects. Being an active member could count towards your professional CPD requirements.

Learn more on **mndassociation.org/cop**.

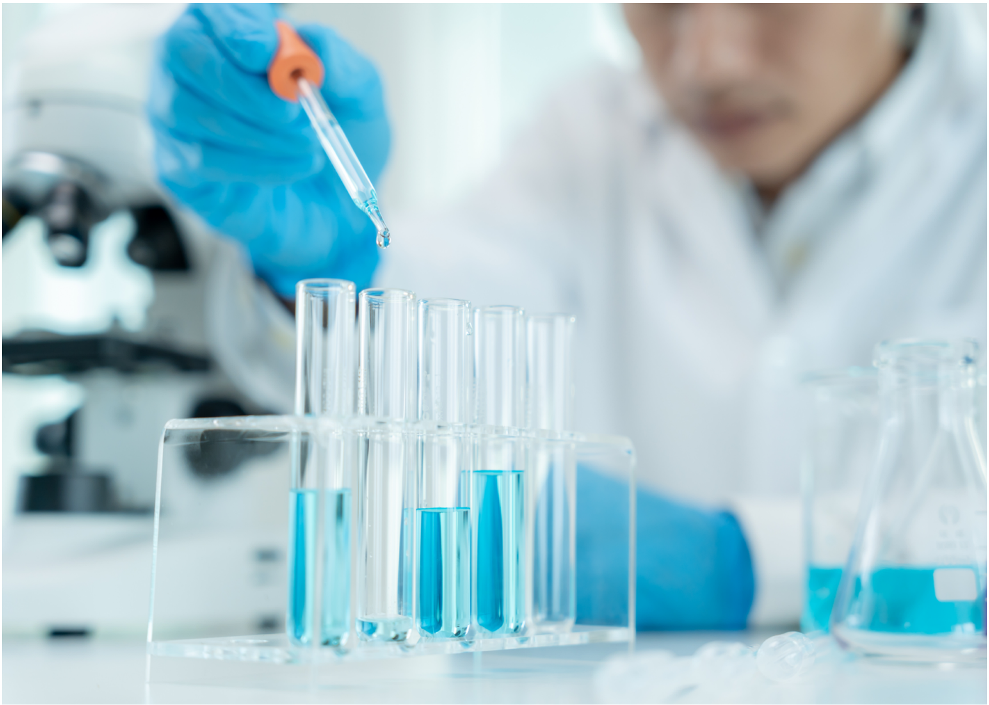
Research into MND

We fund and promote research into understanding the causes and progression of MND, treatments, and improving standards of care. We also produce information resources on research in MND, including information sheets and a research blog.

Additionally, each year we organise the world's largest clinical and biomedical research conference on MND, the International Symposium on ALS/MND. At this event, over 1,000 delegates from at least 30 countries meet to discuss the latest advances in research and clinical management.

Visit **mndassociation.org/research** for further information.

Alternatively, contact the Research Development Team on 01604 611880 or email research@mndassociation.org.



2

Practical support

Financial support

We are able to offer some financial support to help with:

- funding equipment and services that people with MND or Kennedy's disease have been assessed as needing – this includes equipment and services to support with everyday living
- funding technology that people with MND or Kennedy's disease have been assessed as needing, including communication aids such as tablets or apps to use on them
- improving the wellbeing of someone with MND or Kennedy's disease
- supporting the wellbeing of children and young people aged 18 or under and living with someone with MND or Kennedy's disease – funding is available for a limited time post bereavement
- improving the wellbeing of non-paid carers supporting someone with MND or Kennedy's disease – this is also available for a limited time post bereavement
- supporting with the rising cost of living.

The support funds are not in place of any statutory funding, equipment or services that should be available. We can assist with obtaining funding from other charitable organisations.

Visit **mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd** to learn more, or contact MND at mndconnect@mndassociation.org or 0808 802 6262.

Benefits advice service

Our trained advisers can help identify benefits to which a person with MND or Kennedy's disease, or their carer, is entitled. The service is available by telephone or email for people living in England, Wales or Northern Ireland, and there is also a web chat facility for those living in England or Wales.

Visit **mndassociation.org/benefitsadvice** for further details.

Bereavement support

We can offer advice and information for people experiencing bereavement as a result of MND or Kennedy's disease. This webpage also offers signposting to other useful organisations.

Learn more on **mndassociation.org/bereavement**.

Support for Children, Young People and Families

We offer various resources and services to support children and young people, including:

- signposting to specialist services for children and families, such as bereavement support
- free online counselling through our partnership with Barnardo's
- memory boxes for children to create, capture and store memories of their loved ones
- our guide for health and social care professionals "Supporting children and young people close to someone with MND".

We also have information on how to help children and young people better understand the changes happening around them, including child friendly explanations of MND. We have dedicated webpages for:

- children aged 4–10 – resources include MND Buddies, a team of online characters that can help children understand MND through games, stories and online activities. **mndbuddies.org**
- young people aged 11–18
- young people aged 10–25.

To find out more email cyp@mndassociation.org
or visit **mndassociation.org/cyp**.

3

Local support

Regional staff

We have a network of regional staff covering England, Wales and Northern Ireland.

Community Support Co-ordinators (CSCs) cover a distinct geographical area. They manage and lead local volunteers to ensure that the best possible support is provided to people with MND or Kennedy's disease. They develop and support our branches and groups, and help resolve local issues.

Service Development Managers (SDMs) seek to improve and develop services to ensure better outcomes are achieved for people affected by MND. They manage the resolution of complex issues.

Contact details for regional staff are available through the MND Connect helpline. Email mndconnect@mndassociation.org or call 0808 802 6262.

MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Visit **mndassociation.org/care-centres** for further information.

Branches and groups

We have volunteer-led branches and groups across England, Wales and Northern Ireland. They provide local support and help to people with MND or Kennedy's disease and their carers, including peer-support groups. Visit **mndassociation.org/support-and-information/local-support/branches** to find details of your local branch or group.

Association visitors (AVs)

Association visitors provide one-to-one support, information and advice to people affected by MND or Kennedy's disease.

They are experienced volunteers who can visit people within their homes or contact them by telephone, email or through local support groups. They can also provide a link with care centres and other health and social care professionals.

Visit **mndassociation.org/support-and-information/local-support/association-visitors** to learn more.

We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to **education@mndassociation.org**.

If you would like to help us by reviewing future versions of our information resources, please email us at **education@mndassociation.org**.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call **0808 802 6262** or email **mndconnect@mndassociation.org**.

Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

Created: April 2026
Next review: April 2029
Version: 1

**Every day we support people affected
by Motor Neurone Disease.
Because with MND, every day matters.**