



**MND Association
support for health and
social care professionals**

The MND Association supports health and social care professionals to provide the best possible care for people living with motor neurone disease (MND), their carers and families. We do this in a number of ways:

MND Connect Helpline

Our helpline offers information and support on all aspects of MND, including:

- how to manage 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 - 5pm and 7pm - 10:30pm. Calls to this number are free from landlines and mobile phones within the UK, and do not appear on itemised bills.

The helpline offers support to people living with MND, carers, family members, health and social care professionals and volunteers.

Contact the team by emailing mndconnect@mndassociation.org or call 0808 802 6262.

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND, including carers, children and young people.



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

Professionals can obtain this information to supply to people with MND, their family and carers, or to open conversations.

Downloads of our publications are available from our website at www.mndassociation.org/publications

You can also order our publications directly from the MND Connect team. Email mndconnect@mndassociation.org or call 0808 802 6262.

The following links may also be useful:

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

Education

Our education programme is designed to support health and social care professionals to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules, webinars and masterclasses.

Find out more at www.mndassociation.org/education

Community of Practice

The MND Professionals' Community of Practice is a peer led group of health and social care professionals encouraging and supporting the development of good care for people living with or affected by MND.

The community supports professional development, champions collaboration, cross disciplinary awareness and engagement, and develops and shares resources, knowledge and good practice.

Being an active member could count towards your professional CPD requirement.

As a member you can present your ideas directly to the membership at Information and Knowledge Exchange events. These events are an opportunity to network and share your experience with your Community of Practice colleagues.

Find out more at www.mndassociation.org/community-of-practice

Financial support grants

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

- funding equipment and services that people with MND have been assessed as needing
- funding for children and young people aged 18 and under, living with someone with MND, available up to 12 months after bereavement
- non-paid carers supporting someone with MND, available up to 12 months after bereavement
- improving quality of life for someone with MND.

These are not in place of any statutory funding that should be available, however we can assist with obtaining statutory funding or funding from other charitable organisations.

Visit www.mndassociation.org/financial-support for details, or contact MND Connect. Email mndconnect@mndassociation.org or call 0808 802 6262.

Wheelchair service

If you are seeking information about wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, the MND Association's wheelchair service may be able to help through training, joint assessments, advice or support.

For our wheelchair service, please call MND Connect on 0808 802 6262 or email wheelchairs@mndassociation.org

Equipment loan service

We provide a loan service that can help with a limited range of equipment where it is not readily available from a statutory source. The items that we are normally able to support people with are communication aids and voice banking equipment (see next heading). Referrals for equipment loan must be made by a relevant health or social care professional.

Visit www.mndassociation.org/equipment-loan for further details. Alternatively, contact our MND Connect Helpline. Email mndconnect@mndassociation.org or call 0808 802 6262.

Communication aids service

This service helps people with MND, carers, families and health and social care professionals, with queries about communication aids.

The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services.

Our aim is to improve provision and information at a local and national level, through collaboration with health and social care professionals. To contact the service, call 01604 611767 or email communicationaids@mndassociation.org

Research into MND

We fund and promote research into understanding the causes and progression of MND, treatments, and improving standards of care.

Visit www.mndassociation.org/research for further information. Alternatively, contact the Research Development Team on 01604 611880 or email research@mndassociation.org

Visit our research blog at <https://mndresearch.blog>

International Symposium on ALS/MND

Each year we organise the world's largest clinical and biomedical research conference on MND.

It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management, usually attracting more than 800 delegates from at least 30 countries.

In 2020, the Symposium was held online for the first time and attracted a record-breaking 1,800 delegates from over 40 countries.

Find out more at www.mndassociation.org/symposium

MND Association membership

Join us now and help fight MND. Membership fees are discretionary. As a member, you will receive:

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

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

Local support

Regional staff

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

Area Support Co-ordinators (ASCs) cover a distinct geographical area. They manage and lead local volunteers to ensure that the best possible support is provided to people affected by MND. They resolve local issues and develop and maintain local relationships with health and social care professionals.

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.

Visit www.mndassociation.org/responsive to find out more about our regional staff roles. Contact details for regional staff are available through the MND Connect helpline. Call 0808 802 6262 or email mndconnect@mndassociation.org

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 www.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 and their carers.

Visit www.mndassociation.org/branches to find details of your local branch or group.

Association visitors (AVs)

Association visitors provide one-to-one emotional support, information and advice to people affected by MND.

They are volunteers with experience of MND 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 www.mndassociation.org/association-visitors for further information.

Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

MND Association

Tel: 01604 250505

Email: enquiries@mndassociation.org

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