



# Our 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) or Kennedy's disease, 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 or Kennedy's disease, 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 from 10 am to 4 pm. 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 or Kennedy's disease, carers, family members, health and social care professionals and volunteers.

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

#### **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:

- www.mndassociation.org/professionals our main hub for health and social care professionals
- www.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 the people you support:

- 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.



#### Information resources

We produce high quality information resources for health and social care professionals who work with people with MND or Kennedy's disease. 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.



#### **Information Finder Tools**

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

Care information finder - allows people with or affected by MND or Kennedy's disease to select the topic they are interested in, and be presented with a links to the relevant information. It includes a function that allows the person to email the results to themselves or someone else. Find the tool at www.mndassociation.org/careinfofinder

**Professional information finder** - works the same as the care information finder, with the addition of searching for information specifically for a profession, such as occupational therapists. The results include information for professionals and for the people they support. Visit **www.mndassociation.org/pro-info-finder** to use the tool.

#### 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, workshops 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 or Kennedy's disease have been assessed as needing
- funding for children and young people aged 18 and under, living with someone with MND or Kennedy's disease, available up to 12 months after bereavement
- non-paid carers supporting someone with MND or Kennedy's disease, available up to 12 months after bereavement
- improving quality of life for someone with MND or Kennedy's disease.

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.

# **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 page). Referrals for equipment loan must be made by a relevant 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.

#### Wheelchair service

If you want information about wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND or Kennedy's disease, our 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 wheelchairqueries@mndassociation.org

#### Communication aids service

This service helps people with MND or Kennedy's disease, 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

#### Benefits advice service

Our trained advisers can help identify benefits a person may be able to claim if living with MND or Kennedy's disease, or if they are a carer. 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 www.mndassociation.org/benefitsadvice for further details.



#### 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 1,000 delegates from at least 30 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.



# 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 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. 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 or Kennedy's disease 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 or Kennedy's disease.

They are with 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 www.mndassociation.org/association-visitors for further information.

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

**MND** Association

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