

## 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

Accredited by the Helplines Partnership Standard, our dedicated service offers information and support, along with signposting to other services and organisations. The helpline is for people living with MND, carers, family members, health and social care professionals and volunteers. Please contact our freephone line **0808 802 6262** or email us at **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**



### 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. Our care information is accredited by the Information Standard. Health and social care professionals can order this information to supply to people with MND, their family and carers, or to open conversations.

The range includes a suite of guides that give an overview of MND:

- *An easy read guide to motor neurone disease*
- *An introduction to motor neurone disease*
- *Living with motor neurone disease*
- *End of life: a guide for people with motor neurone disease.*



Downloads of all our information sheets and most of our publications are available from our website at **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**. You can also order our publications directly from the MND Connect team.

### Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training, such as conferences and masterclasses. Visit **[www.mndassociation.org/education](http://www.mndassociation.org/education)**

## MND Association website

Access information for health and social care professionals on our website at **[www.mndassociation.org/professionals](http://www.mndassociation.org/professionals)**

## MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Our support grant service provides care and quality of life grants for people with MND. This process is supported by MND Association branch and group funds, and the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with MND with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional.

To find out more about MND support grants or equipment loan, please visit **[www.mndassociation.org/getting-help](http://www.mndassociation.org/getting-help)**, call MND Connect on **0808 8026262** or email **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

## 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 on a local and national level, through collaboration with health and social care professionals. To find out more call MND Connect on **0808 8026262** or email **[communicationaids@mndassociation.org](mailto:communicationaids@mndassociation.org)**

## Wheelchair service

If you are seeking information on 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**

## Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure.

Recent findings have helped us to identify several causes of MND. These findings have helped to improve diagnosis and accelerate new treatment strategies, which have improved the quality of life for people with MND. For more information, contact the Research Development team on **01604 611880** or **research@mndassociation.org**. Alternatively, visit **www.mndassociation.org/research**

For the latest research news, visit our research blog at **www.mndresearch.blog**

For updated information on clinical trials, visit **www.mndassociation.org/treatment-trials**

Our peer-to-peer research and care community blog (ReCCoB) reports on MND-related workshops and events around the world. Subscribe for email alerts at **www.reccob.wordpress.com**

## 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, attracting over 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 costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. You will receive:

- a welcome pack with a membership card and a choice of awareness items
- an optional link to your nearest branch or group
- our quarterly membership magazine, Thumb Print
- an invitation to attend and vote at our AGMs
- invitations to our exclusive conferences and events.

Call **01604 611855** or email **membership@mndassociation.org**

## **Local support**

### **Regional care development advisers**

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

### **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.

### **Branches and groups**

We have volunteer-led branches and groups nationwide. They provide local support and practical help to people with MND and their carers.

### **Association visitors (AVs)**

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND 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.

## About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

## Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

## MND Association

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[www.mndassociation.org](http://www.mndassociation.org)



@mndeducation



/mndassociation

## About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.

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