Motor Neurone Disease Association
Key messages and core information
May 2023

Contents

Source: MND Association Impact Report 2022

Our vision

A world free from MND.

Our Promises

To harness the hope within our community to speed up progress towards a world free from MND, the MND Association has committed to five Promises.

Our Promises give us focus to work faster and fight harder to strive for better – together with our community. Simply put, they drive everything we do.

We promise we won’t rest until:

- MND is treatable and ultimately curable
- Everyone gets the care they need when they need it
- Every day with MND counts
- You are heard
- No one faces MND alone.

Our values

- People with MND, their families and carers are at the **heart** of everything we do.

- We **collaborate**, and value everyone’s contribution.

- We achieve excellence through personal **commitment** and ongoing improvement.

- We **respect** and respond to people’s diverse needs, backgrounds and views.

- We achieve our aims through building **open** and transparent relationships.

About motor neurone disease (MND) – key facts

If you require more information on the statistics below, please contact the MND Association's communications team: communications@mndassociation.org.

- 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, hearing, touch etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND experience changes to their speech, which may become slurred or quieter. Some people lose their ability to speak entirely.
- It affects people from all backgrounds.
- Around 50% of people with MND experience some form of cognitive change while living with the disease. This can affect their thinking or behaviour. This percentage rises to around 80% for people who are in the advanced stages of the disease.
- It 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 around 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- It affects more than 5,000 adults in the UK at any one time.
- It kills six people per day in the UK, this is just under 2,200 per year.
- It has no cure.

About the MND Association - our reach

The MND Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland.

We fund a number of roles that provide the co-ordination and delivery of care at 22 MND care centres and networks across England, Wales, and Northern Ireland. These are developed in partnership with the NHS and provide co-ordinated multidisciplinary care which has been shown to improve quality of life and life expectancy for people with MND.

At the end of 2022, 3,972 people with MND were being supported by an Association-funded care centre or network.

We fund research into MND and support scientific and clinical research communities in the UK and worldwide. We organise an annual research conference, the International Symposium on ALS/MND, which is the largest medical and scientific conference specific to MND. Our latest Symposium in December 2022, held virtually, attracted 1292 delegates from 44 countries.

We have over 11,000 members helping to strengthen our voice to ensure everyone with MND has access to the best possible care.

Our 90 volunteer-led branches and groups provide local support to people with MND, their families and carers. A growing number also hold separate support meetings for carers.

We have over 300 Association visitors and care service navigators who provide support to people affected by MND.

We employ around 200 staff, whose specialist skills and knowledge are dedicated to improving the lives of people affected by MND.

We support hundreds of health and social care professionals who provide and manage services for people with MND through specialist education events and information provision.

We lobby the Government in London, the Welsh Government and the Northern Ireland Executive to ensure national policy reflects the needs of people affected by MND. We also campaign in coalition with other charities, through the Care and Support Alliance, the Association of Medical Research Charities, MND Scotland and others.

We are an active founder member of the International Alliance of ALS/MND Associations.

Our social media platforms are vital in helping us communicate the impact of our work. In 2022, across all of our social media accounts, we had 1.8 million likes, shares and retweets, and we now have more than 64,000 followers on Facebook and 44,000 followers on Twitter. In the same year, our website received over 2 million visits and we distributed 34,500 copies of our *Thumb Print* magazine to Association members across England, Wales and Northern Ireland. Our podcast, *MND Matters*, had more than 5000 plays in 2022.

Our work is made possible by huge support from volunteers and is kindly funded by supporters who donate and fundraise on our behalf.

About MND – standard description – (150 words)

To follow is a standard description of MND that may be useful when writing about the disease:

Motor neurone disease (MND) is a fatal, rapidly progressing neurological condition affecting more than 5,000 adults in the UK at any one time. The disease causes messages from nerves (motor neurones) in the brain and spinal cord that control movement to gradually stop reaching the muscles, leading them to weaken, stiffen and waste.

The result is that people become locked in a failing body, unable to move, talk and eventually breathe. Some may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia. MND does not usually affect senses such as sight, hearing and touch.

MND kills a third of people within a year and more than half within two years of diagnosis. It affects people from all backgrounds and a person's lifetime risk of developing MND around 1 in 300. Today six people will be diagnosed and six will die from MND. There is no cure.

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About the MND Association – standard description (100 words)

To follow are standard descriptions of the Association that may be useful when describing our work:

The MND Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland. We have over 11,000 members forming a powerful network that provides information 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. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

People with MND, their families and carers are at the heart of everything we do.

About the MND Association – standard description (400 words)

The Motor Neurone Disease (MND) Association was founded in 1979 by volunteers who had experience of living with or caring for someone with MND. Since then, we have grown considerably with a community of volunteers, supporters and staff, all sharing the same goal - to support people with MND and everyone who cares for them, now and in the future. The Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland.

The Association provides support to approximately 3,900 people through our MND Care and Research Centre Network, developed in partnership with the NHS. We also provide around £1.5m in financial grants annually, with almost 2000 people benefitting from the service last year. Our MND Connect helpline provided support on more than 10,000 telephone calls with our community last year, and received almost 5000 emails. We also work with and educate health and social care professionals, to enable them to provide the very best care and support to people affected by MND.

Local support is provided by our network of 90 branches and groups, where people living with MND, their carers and families can access vital information and meet other members of the MND community. Working alongside our branch and group network are area support co-ordinators, who work with a team of around 300 Association visitors who, as volunteers, provide support to people with MND and their family and carers.

The Association is committed to funding and promoting research that leads to a better understanding of MND, potential treatments and ultimately, a cure. The value of our research grant portfolio on 31 December 2022 was around £20m, and we currently fund 104 research grants.

We are an active member of the International Alliance of MND/ALS Associations and we organise the largest annual research conference on MND – the International Symposium of ALS/MND, a showcase of the latest scientific research and learning from clinicians and researchers from around the world.

We actively campaign and lobby the Government in London, the Welsh Assembly, the Northern Ireland Executive and local councils, to ensure the needs of people affected by MND are being met. We do this in collaboration with our network of 11,000 committed campaign volunteers and focus our efforts on those decision makers best placed to make the biggest difference to people with MND.

People with MND are at the heart of everything we do.

About MND and the work of the Association – emotive description (500 words)

Today in the UK, six people will hear the devastating news that they have motor neurone disease (MND). In that instant, their world – and the world of their loved ones - is shattered.

MND attacks the nerves, leaving those affected unable to walk, talk, eat and ultimately to breathe. It usually progresses rapidly and there is currently no effective treatment or cure. One third of people with MND die within a year and over half within two years of diagnosis. Despite its devastating impact, MND remains a little understood condition. A diagnosis of MND is extremely frightening, leaving those affected unsure of what to do next and where to turn. Without the right support, they can be left feeling fearful, isolated and alone.

The MND Association is here to support people facing that unimaginable diagnosis, as well as their loved ones and their carers. Founded in 1979 by volunteers, our tenacious community has grown considerably, all sharing the same vision – a world free from MND. The MND Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland.

To harness the hope within our community to speed up progress towards a world free from MND, the MND Association has committed to five Promises. They give us focus to work faster and fight harder to strive for better – together with our community.

We promise, we will not rest until:

- MND is treatable and ultimately curable
- Everyone gets the care they need, when they need it
- Every day with MND counts
- You are heard
- No one faces MND alone.

Our support activities for people affected by MND include:

- A network of multi-disciplinary Care Centres which provides high quality coordinated care from expert professionals.
- A telephone and email helpline staffed by experts providing essential frontline support.
- A network of regional staff and volunteers providing support to people with MND and education to care-providers.
- Equipment loans, including communication aids, that improves quality of life for those with the disease.
- Association visitors – volunteers who are experienced with the disease and are friends for those affected by MND.

The MND Association is proud to take a leading role in the global fight against MND by funding ground-breaking research, facilitating collaboration, and raising vital awareness. We fund biomedical research into the causes of MND, the search for a diagnostic test and a cure, we also fund healthcare research to improve the lives of people living with MND. The value of our research grant portfolio on 31 December 2022 was around £20m, and we are currently funding 104 research grants. We also have the largest advocacy network for people with MND in the country, and lobby the Government in London, the Welsh Government and the Northern Ireland Executive to ensure national policy reflects the needs of people affected by MND.

People with MND are at the heart of everything we do.