Motor Neurone Disease Association
Key messages and core information
May 2025

Contents

Source: [MND Association Impact Report 2024]

Our vision

A world free from MND.

Our Strategy

Our Strategy is built around three interlinked Impact Goals, which together will create lasting change.

Tomorrow's Treatment
We will accelerate progress towards effective treatments by investing in world-leading science, supporting the brightest researchers, and ensuring people with MND are diagnosed faster and have access to effective and proven treatments. Our goal is to turn understanding into breakthroughs - and breakthroughs into treatments.

My Support, My Way
We will put people with MND and their carers at the centre of everything we do - offering tailored, timely support that reflects individual needs and experiences. From emotional wellbeing and practical help to clearer, more connected services, we are committed to helping people live well, for longer.

Influence High Quality Care
We will push for consistently high-quality, personalised care for everyone with MND. By working with partners, influencing policy, and leading national campaigns, we will tackle systemic inequalities and ensure care and support systems meet the real needs of people affected by MND.

Read our full Strategy document.

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 24 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. In 2024, over 3,500 people with MND were supported by an Association-funded care centre or network.

We are proud to take a leading role in the global fight against MND by funding groundbreaking research into the disease and facilitating important collaboration between researchers. We organise the International Symposium on ALS/MND, the largest medical and scientific conference on the disease, which attracts delegates from across the world to share the latest advances in research and treatment. Last year, we welcomed 1500 people to our Symposium from 48 different countries.

We have almost 13,000 members helping to strengthen our voice to ensure everyone with MND has access to the best possible care.

Our 87 volunteer-led branches and groups provide local support to people with MND, their families and carers. In total, we run 135 different support groups across England, Wales and Northern Ireland, with the majority of these taking place face-to-face.

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

We employ around 275 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, and alongside MND Scotland, My Name’5 Doddie Foundation and others.

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

Our social media accounts are vital in helping us communicate the impact of our work. Across all of our platforms - Facebook, Twitter, Instagram and TikTok - we have more than 176,000 followers.

We receive around 760,000 unique visits to our website annually and last year distributed 41,000 copies of our *Thumb Print* magazine to Association members. We’ve now produced more than 30 episodes of our podcast, *MND Matters*, with over 18,000 listens across all episodes.

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 is around 1 in 300. Today, six people will be diagnosed and six will die from MND. There is no cure.

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 is the leading charity in England, Wales and Northern Ireland focused on funding research, improving access to care and campaigning for people living with or affected by MND. We have over 13,000 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, 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 vision - a world free from MND.

The Association provides support to approximately 3,900 people through our MND Care and Research Centre Network, developed in partnership with the NHS. Last year we gave a total of £3m in financial grants to more than 3,100 people with and affected by MND.

In 2024, we funded 712 tailored counselling sessions for children and young people who have a loved one with the disease, and our MND Connect helpline answered more than 7,000 enquiries from people needing information or support. 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 87 branches and groups, where people affected by MND 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. They, as volunteers, provide invaluable 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. We are the biggest charity funder of targeted MND research, with the value of our research grant portfolio at the end of 2024 totalling £24.2m, funding 133 research grants.

We are an active member of the International Alliance of MND/ALS Associations and 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 16,000 committed campaigners and focus our efforts on those decision makers best placed to make the biggest difference to people with MND.

People with MND, their families and carers 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 eventually 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.

The Association is proud to take a leading role in the global fight against MND by funding groundbreaking 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, and we also fund healthcare research to improve the lives of people living with MND. The value of our research grant portfolio on 31 December 2024 was £24.2m, funding 133 research grants.

For 45 years, the Association has provided essential support for people affected by MND, and this provision continues to increase thanks to generous voluntary donations. We fund several roles that provide the co-ordination and delivery of care at 24 MND care centres and networks, and offer a comprehensive financial support grant programme which is accessible for people with MND, their carers and young people affected by the disease.

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.

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