

Motor Neurone Disease Association

Key messages and core information

June 2020

Contents

Our vision	2
Our mission	2
Our values	2
About Motor Neurone Disease (MND) – key facts	3
About the MND Association - our reach	4
About MND – standard description (150 words)	5
About the MND Association – standard description (100 words)	5
About the MND Association – standard description (400 words)	6
About MND and the work of the Association – emotive description (500 words)	7

Source: [MND Association Impact Report](#)

Our vision

A world free from MND.

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.

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 will have communication difficulties, for most this means a complete loss of voice.
- It affects people from all backgrounds.
- Around 35% of people with MND experience mild [cognitive change](#), in other words, changes in thinking and behaviour. A further 15% of people show signs of [frontotemporal dementia](#) which results in more pronounced behavioural change.
- 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 up to 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 is the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

We fund coordination of care within our 22 MND care centres and networks. These provide coordinated multi-disciplinary care which has been shown to improve quality of life and life expectancy for those with MND.

As at December 2019, 3,931 people with MND were being supported by an Associated 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. Held in Perth, Australia in 2019, the Symposium attracted over 850 delegates from 33 countries.

We have over 10,000 members helping to strengthen our voice to ensure everyone with MND has access to the best possible care.

Our 89 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 180 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 2019, likes on Facebook increased to 40,348 and we now have 30,158 followers on Twitter. Our website received over 2 million visits and our *Thumb Print* magazine is sent to over 8,800 Association members across England, Wales and Northern Ireland.

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 up to 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.

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 Motor Neurone Disease Association is the only national charity in England, Wales and Northern Ireland focused on improving care, research and campaigning. We have over 10,000 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 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 considerably 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, now and in the future. We are the only national MND charity in England, Wales and Northern Ireland focused on improving care, research and campaigning.

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 £1.2m in support grants annually, and loaned equipment to over 1,700 people last year. We responded to over 7,600 requests for information and support through our dedicated helpline. 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 89 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.

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.

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 whole research grant portfolio on 31 December 2019 was around £14m, and we are currently funding 83 research grants.

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 7,000 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 lose their life within a year and over half within two years of diagnosis.

The vision of the MND Association is a world free from MND. 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. Many people with MND can deteriorate incredibly quickly, so it is vitally important for them to get the support of specialists in a range of areas as quickly as possible. People with MND can often be in touch with up to 20 different health and social care professionals at any one time, therefore a co-ordinated multi-disciplinary approach is vital.

Founded in 1979, our mission is three-fold:

- We invest in research that will help us increase understanding of the disease, develop treatments and ultimately a cure.
- We provide expert support and information that helps people to live as well as possible, for as long as possible.
- 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.

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 equipment 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.

We are a leader in the funding and promotion of pioneering research into MND. The Association funds 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 whole research grant portfolio on 31 December 2019 was around £14m, and we are currently funding 83 research grants.

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. An outcome of our campaigning was the publication of a NICE (National Institute for Health and Care Excellence) guideline on MND. This sets out what good care looks like including how it should be delivered by statutory services and we are using it to shape future care provision.

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