



BEATING MND TOGETHER

A COMMUNITY POWERED BY HOPE

If you care about MND, you're not alone.

The MND Association is a community powered by hope. We are volunteers, people with MND and their families, fundraisers, donors, supporters, members, campaigners, trustees and staff. All focused on supporting and standing with those diagnosed, and with those who look after and love them. And all working towards our vision of a world free from MND.

We are also at the heart of a wider MND movement. Connected to researchers, clinicians, health and social care professionals, technology and pharmaceutical companies, other MND charities, Government decision-makers and many, many more people who understand the impact of MND and share our desire for change.

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Add it all up, and that's thousands of people.

Alone, each of us can only do so much against a disease that claims six more lives every day.

Together we can be powerful.

TOGETHER WE CAN BE POWERFUL

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mnda motor neuronedisease We last committed to a set of Association-wide goals in 2017. We've achieved a lot since then. There is increasing confidence that we're on the brink of discovering effective treatments. This is due to a far greater scientific knowledge of MND, in particular, the roles that genes play in both health and disease.

Our Next Generation Think Tank has brought together technology giants like Rolls-Royce, Google and Dell, potentially revolutionising everyday life and communication for people with MND.

We've expanded our support so that it's not just people with MND we focus on and fight for, but also carers and families, including children and young people.

Public awareness is at a new high (though still not high enough), and we've persuaded the Government to improve support for working-age people with MND via a landmark change to the welfare system.

In 2021 the United to End MND campaign successfully secured

a commitment from Government to invest £50 million over five years into targeted MND research across UK universities and hospitals. This and other exciting opportunities will build on the momentum generated through many years of the Association funding and facilitating UK and international research.

In 2022, our vision for a world free from MND remains as strong as ever, and we are impatient to bring it about as soon as possible. We won't stop until we've delivered the new promises and ambitions detailed on these pages. They build on the progress we've already made over four decades, thanks to the MND community.

OUR PROMISES WE WON'T REST UNTIL...



We've achieved a lot together in 40 years. Now we're harnessing the hope that powers our community, to speed up progress towards a world free from MND.

We're committing to five big promises.

They've come from talking to our community about what matters most, and they will drive everything we do.

Each promise includes a number of ambitions – together, they set out the future you've told us you want to see.

We're confident we will meet our promises and realise our ambitions. That's in part because we're building on 40 years of progress, and making the most of developments in science and technology that mean we can speed up progress as never before.

It's also because we have a community of people like you, to guide us and amplify our efforts.

We can beat MND together.

PROMISE 1 WE WON'T REST UNTIL MND IS TREATABLE AND ULTIMATELY CURABLE



There's still no treatment that stops MND, or that significantly slows it down. We will build on our respected position as a global leader in MND research, supported by people with MND and the MND research community. We will increase financial investment in MND research from a range of sources, advance scientific knowledge, and turn discoveries into treatments.

OUR AMBITIONS



Everyone who wants to take part in research is able to



People with MND are able to access effective new treatments as quickly as possible



Increased global collaboration and co-ordination of MND research is accelerating progress towards effective treatments



Increased understanding of MND speeds drug discovery and drug development and is delivering more trial opportunities

PROMISE 2 WE WON'T REST UNTIL EVERYONE GETS THE CARE THEY NEED WHEN THEY NEED IT



The quality of your MND care, and even the speed of your diagnosis, still depend too much on where you live and who you see. We will use our influence with clinicians, and with the wider NHS and social care systems, to raise standards throughout England, Wales and Northern Ireland.

OUR AMBITIONS



Time to diagnosis is reduced and research to develop a diagnostic test is prioritised



All people with MND can live fuller lives, through high quality care and support



Everyone diagnosed with MND is signposted to the Association and able to access our services



Everyone can access high quality, co-ordinated multidisciplinary care



All people with MND feel able to make choices about genetic testing and life-extending and enhancing treatments

PROMISE 3 WE WON'T REST UNTIL EVERY DAY WITH MND COUNTS



MND has a devastating impact both on those diagnosed, and those who look after and love them. We'll continue to support people's quality of life, every day they need us. And we will work with global tech leaders to deliver accessible technology so people with MND stay connected.

OUR AMBITIONS



People with MND have choice and control over their support and care



People with MND have a better quality of life



New technology solutions improve quality of life and increase independence of those living with MND



All people with MND, their carers and families receive the support they need when they need it

PROMISE 4 WE WON'T REST UNTIL YOU ARE HEARD



The MND community is a powerful network, and we are proud of the role we play in it. We will find more ways to listen to you, to involve you, and to stand with you. You've told us you want more people to know about MND, and for MND to be prioritised by those who can help make things better. We will focus on this too.

OUR AMBITIONS



Everything we do is influenced by people affected by MND



People come to us as the trusted and honest voice of the MND community



MND is a well-known disease



MND is prioritised amongst decision makers (including politicians, NHS, local authorities and drug companies)

PROMISE 5 WE WON'T REST UNTIL **NO ONE FACES MND ALONE**



The MND community is diverse. Not just because MND affects each person differently, but also because it is present in all communities and among people of all backgrounds. We will do more to respond to the needs of under-served communities, and to involve people affected by MND earlier in designing and planning our work.

OUR AMBITIONS



Our support, and that of our partners, is designed to meet people's many differing needs, including the needs of under-served groups



Increased engagement with diverse communities raises awareness, participation and personalised support



People affected by MND are shaping our priorities and services



Everyone feels valued and welcome in the Association

AN ASSOCIATION CAPABLE OF MAKING IT HAPPEN

How we work within the Association, and with the wider MND community, will influence whether we meet our promises or not. We will get even better at:



Raising and investing the money needed to achieve our ambitions, ensuring we have a sustainable financial platform



Developing our data, technological and digital infrastructure, skills and capabilities, to match our future ambitions



Building our team and involving our community, so we have the people and culture to get the work done

HOLD US TO OUR PROMISES WE WON'T REST UNTIL...





LET'S BEAT MND TOGETHER

Help us meet our promises: www.mndassociation.org/get-involved Join us: www.mndassociation.org/membership



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