

Our Strategy

2025-2030



Introduction

For more than 40 years, the MND Association has led the fight against motor neurone disease - funding groundbreaking research, supporting people affected by the disease, and campaigning for change. We are proud of the progress made, but there is still much to do.

There is still no truly effective treatment for the vast majority of people with MND. Access to care varies significantly by region, and too many people face isolation, disempowerment, and barriers to living the life they choose.

The next five years offer real potential for change. Public awareness has grown - driven by the bravery of those who have shared their stories and galvanised public support. This visibility has fuelled fundraising, enabling us to support more people and invest in the research that will lead to future treatments, and ultimately, a cure.

With greater recognition and income come more choices and new challenges. We must step up to meet those and make clear, strategic choices to maximise our impact and ensure a sustainable future for the Association so we can be here for the people who need us now and in the future.



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

Our Impact Goals



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.

Together, these goals form a single, unified mission:

**To improve the lives of people with MND today,
while building hope for tomorrow.**

Everyone has a role to play. Whether you are living with MND, supporting a loved one, working in care, researching potential treatments, campaigning for change or raising vital funds to support the fight against MND - we invite you to join us. Together, we can create the future people with MND deserve.

Impact Goal: Tomorrow's Treatment

Over the past four decades, the MND Association and our partners have significantly advanced understanding of the biology behind motor neurone disease. Yet despite this progress, MND remains a devastating, terminal illness, and most people living with it still have no access to effective treatment.

Much about the disease remains unknown. Promising treatments often fail during development, diagnoses are too often delayed, and access to clinical trials varies widely across the UK.

Over the next five years, we will focus on four key priorities:

- 1. Deepening our understanding of MND:** We will identify new ways to combat the disease by advancing our knowledge of its causes, progression, and potential treatment targets - paving the way for future breakthroughs.
- 2. Driving faster, more accurate diagnosis:** We will drive innovation in diagnostic testing to ensure everyone with MND receives a prompt diagnosis and genetic profile, unlocking access to timely, tailored treatments.
- 3. Pioneering new treatments and care:** We will play a vital role in translating cutting-edge science into real-world impact - supporting the development of new treatments and improving care through clinical trials and healthcare research.
- 4. Backing the brightest minds in research:** Our investment has already helped build a generation of talented MND researchers. We will continue to attract and support the best scientific minds with training, funding, and world-class research infrastructure - ensuring MND research remains a vibrant, ambitious field.

Impact Goal: My Support, My Way

Connecting with others and accessing the right support at the point of diagnosis can significantly improve both the physical and mental wellbeing of people living with MND. We are proud that our information and support services make a real difference, but we know, too often, help comes too late or isn't coordinated effectively.

Our research shows a third of people with MND feel lonely or isolated. Many struggle to access the right support to help them maintain the friendships, connections, and interests they valued before diagnosis. Others face barriers to securing assistive technology or making vital home adaptations, limiting their independence and quality of life.

Over the next five years, we will focus on four priorities:

- 1. Providing information and support tailored to each person's needs:** We will provide personalised support to people with MND, their carers, and loved ones, ensuring they can access the right services from diagnosis through to end of life.
- 2. Ensuring everyone has the emotional wellbeing and psychological support they need:** Whether through our own services or in partnership with others, we will ensure everyone affected by MND has access to emotional and psychological support, from the moment of diagnosis.
- 3. Practical and financial help when it's needed:** While government should meet the financial needs of people with MND, too often it falls short. Until this changes, we will continue to provide vital financial and practical support, directly and through partners, to help people access the services and assistance they need.
- 4. A more joined-up support experience:** We will integrate and streamline our services to ensure everyone, whether supported by staff or our incredible volunteer network, has a consistent, accessible and joined-up experience.

Impact Goal: Influence High Quality Care

While some people with MND receive excellent care, far too many do not. Across England, Wales and Northern Ireland, the quality of care is inconsistent, creating a postcode lottery where access to vital support depends on where you live. Even where services exist, they are not always joined up or of the standard people with MND have a right to expect.

Over the next five years, we will focus on three priorities:

- 1. Raising standards of care:** We will work with partners to improve the quality and consistency of care for everyone living with MND. This includes funding dedicated care coordinator roles and influencing Care Centres and Networks.
- 2. Shaping policy and practice:** We will influence decision-makers and system leaders at national and regional levels to close the gaps in care and support. Where data and insight are missing, we will collaborate with partners to fill them, ensuring policy is grounded in the real experiences of people affected by MND. We will also be active members of coalitions calling for wider reforms, such as improvements to adult social care and fairer support for unpaid carers.
- 3. Leading bold, evidence-based campaigns:** We will continue to lead campaigns on issues that matter most to the MND community. Whether it's securing access to housing adaptations, expanding availability of genetic testing and counselling, or pushing for new treatments to be made available on the NHS, we will use the power of our collective voice to demand better care and support.

Being the charity the MND community needs

To deliver the scale of ambition we have set out in our impact goals, we also need to evolve how we work as an organisation. Increased public awareness and support have enabled us to grow significantly in recent years. Now, we must ensure we are equipped to operate effectively as a larger, more ambitious charity.

Over the next five years, we will:

- **Grow our annual income** to £50 million by 2030, so we can sustain and expand our research and support work.
- **Improve how people affected by MND are involved** in shaping our decisions and how we work, and ensure we are listening to an inclusive range of voices and views from across our community.
- **Invest in awareness** to deepen public understanding of MND and support our campaigning and fundraising to increase impact and reach.
- **Harness data and technology** to improve efficiency, increase impact and expand our digital engagement.
- **Develop our people and culture** to work more effectively and deliver the greatest possible benefit for our community.

