



Candidate Pack for Chair

Welcome

Dear Candidate,

Thank you for your interest in becoming our new Chair.

The Motor Neurone Disease (MND) Association is dedicated to improving the lives of people affected by MND, now and in the future. We fund research, improve care and provide support for people with MND, their families and carers. As a membership organisation with more than 12,000 members and 13,000 volunteers, we have a powerful national and local network united behind our vision for a world free of MND. People with MND, their families and carers are at the heart of everything we do.

We are entering a very exciting and potentially life changing time for people with MND. With the disease having a high profile and more funds coming into research, we are hoping to see the development of new treatment options in the future, giving hope to our community and allowing them choice and control in managing MND.

Our charity has grown rapidly in recent years and has played a critical role in driving this progress for the MND Community but there is still much more to do. We want to build on our success and ensure we are well positioned for further growth, elevating our profile and extending our reach and impact.

Our new strategy for 2025-2030 is underpinned by three impact goals centred around accelerating progress in treatments for people with MND, influencing high quality care, and keeping people with MND and their carers at the heart of everything we do. The next five years offer real potential for change.

As our new Chair, you will help us steer a period of strategic development that is bold and ambitious in its pursuit of excellence on behalf of people with MND. You will be leading excellent and committed Board colleagues and working with our Chief Executive Officer (CEO) and her team to seize the opportunities and handle the inevitable growing pains inherent in change and expansion. Outside the organisation, you will be a trusted and persuasive ambassador with a range of stakeholders including policy makers, opinion formers and partners.

The successful candidate will share our drive to create a world free of MND and empathise with the issues ahead for an organisation like ours. You needn't be from the health sector to play your part as Chair; however, you will understand the complexities of leading a significant organisation going through change.

We're looking for a successful and commercially astute senior leader who understands this role and what it means to chair a growing organisation in an environment that is often highly challenging and emotive. An intuitive understanding of good governance will also be essential, along with an accessible and personally flexible style. We're driven by our vision, and see the collective of Executive and Trustee voices working as a unitary Board as the most effective route to achieving it. Someone collegiate who builds rapport and works through relationships will be the best fit for us.

If you think you bring what we are looking for and feel as passionate as we do about our work, we hope you will read on to find out more.

The Board of Trustees, MND Association

About MND and the work of the Association

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 many 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.

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. Our network of members 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

To read our new five-year strategy, Impact and Annual Report please click [here](#)



Our vision and values

Our vision

A world free from MND.

Our Values

- We're One Strong Team
- We Make Every Day Count
- We Think Big
- We Are Determined

Commitment to Diversity

We encourage applications from individuals with diverse backgrounds, skills, and perspectives to help us better serve the charity's mission and beneficiaries.

MND doesn't discriminate, and neither do we.

We are determined to become fully inclusive by continuing to embrace diversity, remaining committed to equity and ensuring that our products and services are fully accessible. In this way, we can ensure that all people living with and affected by MND get the best possible care and support they deserve.

We offer a variety of network groups and forums that are open to everyone, including our staff, volunteers, people living with and affected by MND, as well as Association members. These groups provide peer-to-peer support, raise awareness, and hold the Association accountable.

We are a Stonewall Diversity Champion, have recently been awarded Disability Confident-Employer status, and are members of the Communications Access Scheme.

Take a look at the [inclusion pages](#) on our website to learn more about our inclusion strategy, see how far we've come and where we are heading.

Our governance

As a membership organisation, our members have a say in how we are run and play a key role in the governance of the Association. The Association has two types of Trustees, Elected Trustees and Co-Opted Trustees. Elected Trustees are voted for by our members. Those receiving the greatest number of votes fill the vacancies on the Board and are announced at the Annual General Meeting each year. Co-Opted Trustees are openly advertised positions and are approved by the Board of Trustees. Co-Opted Trustees do not stand for election but are appointed by the Board following an open recruitment process. In the case of the Chair, the preferred candidate is presented by the Board of Trustees to the membership for election.

Their leadership ensures we continue to support people living with MND, their carers, and families while research into effective treatments progresses.

For further information on our current Board Members, please [click here](#).

Role Description

Role title: Chair of the Board of Trustees

Role Purpose

The Chair provides strategic leadership to the Board of Trustees, working with and guiding the Chief Executive, collectively ensuring the delivery of the organisation's charitable objects, vision and mission.

Main responsibilities

Strategic leadership, constructive challenge and oversight

- Providing strategic leadership and insights to the Board, its Committees, the CEO and Executive Leadership Team (ELT) to ensure the alignment of the charitable purposes, mission, vision, and values of the charity support agreed strategic priorities
- Supporting/leading the Board to collaborate with the ELT and key stakeholders to develop and implement long-term strategies that advance the charity's objects, impact and sustainability
- Discussing and agreeing the risk appetite of the Board and ensuring major risks and opportunities are regularly reviewed and addressed within the agreed risk management framework
- Ensuring that the impact and effectiveness of the MND Association's activities are measured and reported to the Board in accordance with agreed performance monitoring arrangements
- Promoting innovation within the MND Association to stay ahead in the field of research and support
- Leading Board meetings to ensure high-quality, inclusive debate and well-informed, timely decision-making in the best interests of the MND Association
- Ensuring Trustees are fully engaged and supported to contribute effectively, and take collective ownership of decisions made
- Working closely with Committee Chairs to ensure their delegated remits are met
- Working with the Chief Executive and Company Secretary/Head of Governance and Compliance to plan meetings and agendas, ensuring decisions are implemented and monitored and ensuring that the business is covered efficiently and effectively
- Ensuring, in liaison with the Company Secretary/Head of Governance and Compliance, that appropriate procedures, processes and controls are in place and followed.

Stakeholder engagement and accountability

- Representing the MND Association to partners and key stakeholders, including members, regulators, partner organisations in the health and research community, policy makers, funders, and opinion formers
- Building and maintaining close relations between the charity's various constituencies and stakeholder groups to promote the effective operation of the charity's activities
- Chairing the annual general meeting (AGM) of members, facilitating the membership in holding the Board to account for its decisions and actions
- Cultivating positive and constructive relationships among individual Trustees and between Trustees and the ELT.

Performance, development and diversity

- Ensuring that the Board has the necessary diversity of skills, expertise, life experiences, behaviours and competencies to perform their functions in line with the law, regulatory requirements and the best interests of the charity
- Encouraging all Trustees to contribute positively to their individual roles and that of the Board, ensuring constructive challenge, robust scrutiny and range of views are welcomed to demonstrate sound decision-making
- Upholding the values of the charity by example, and ensuring that the organisation promotes equality, diversity and inclusion creating a welcoming board environment that values diversity of experience, backgrounds and thinking to create better decisions for the direction of the charity
- Committing to good governance practices, ensuring the regular review of internal policies, procedures and behaviours to deliver the highest standards of performance and propriety
- Ensuring, with the support of the CEO, ELT and Company Secretary/Head of Governance and Compliance, compliance with statutory requirements and that the organisation pursues its objectives as defined in its Articles of Association
- Developing the culture, knowledge, and capability of the Board, ensuring ongoing development and conducting annual appraisals with Board members and ensuring effective succession planning
- Ensuring the Company Secretary/Head of Governance and Compliance undertake regular reviews of Board, Committee and governance effectiveness, reporting outcomes to the Board.

Oversight and support of the CEO

- Providing leadership and support to the CEO for their personal development and benefit of the charity
- Supporting and annually appraising the performance of the CEO
- Supporting and encouraging the CEO in their talent pipeline and succession planning activities, with the input of relevant Board committees
- Maintaining regular, open communication with the CEO, providing a sounding board and being alive to emerging priorities.



Person Description

Part One: Knowledge and experience

- Considerable non-executive experience, gained as a Chair or Vice Chair - charity, public or commercial sector
- Significant experience of strategic leadership in a complex organisation undergoing growth and change
- Strong experience representing organisations externally from public platforms and through effective stakeholder management, with a demonstrable breadth of networks
- Strong knowledge of the principles of good governance and financial oversight, and the respective roles of the Board and Executive
- Knowledgeable about Board development, with experience of promoting the development of Board diversity and effectiveness
- Knowledge / understanding of MND is desirable.

Part Two: Skills and abilities

- Highly effective skills in positioning, persuading and influencing
- An excellent and engaging communicator with advanced interpersonal skills
- Able to see the bigger picture and to think strategically
- Able to lead a diverse board, reconciling differing perspectives and achieving progress
- Exceptional chairing skills; able to facilitate discussion and debate amongst an accomplished group of Board members.

Part Three: Leadership style and behaviours

- Demonstrable evidence of the Nolan Principles of leadership
- Strategic vision and financial acumen
- Collegiate style; high capacity for self-reflection and is emotionally intelligent
- Personally flexible and adaptable
- Undisputed personal stature, presence, and integrity, sound judgement
- Fosters group and collective accountability and a good role model who sets the tone for the organisation
- Deep commitment to the mission and values of the MND Association.



Terms of appointment

Remuneration

This is a voluntary position, with reasonable expenses paid.

Location

Any in person meetings will be held at either our Northampton or London offices. Travel to other locations/external events will be required.

Time Commitment

This role requires around 2-3 days per month, which includes:

- Four board meetings at our offices in Northampton or London.
- An in-person Board Away Day also occurs once per year, usually in September.
- Quarterly sub-committee meetings operate in a hybrid format to ensure inclusivity and accessibility.
- Monthly Honorary Officers Group (HoG) meeting which operate in a hybrid format.

Term of Appointment

The Chair is appointed for two terms of four years.

How to apply

To make an application, please go to <https://starfishsearch.com/jobs/mnda-chair/> and click on the apply now button, with the following prepared:

- Your CV (no more than three sides).
- A covering letter that sets out your motivation for the role and describes the specific experience you can bring to the appointment.

We would also be grateful if you would complete the Equality and Diversity monitoring form on the online application process. This form is for monitoring purposes only and is not treated as part of your application.

Recruitment timetable

Closing date:	Friday 31st October 2025
Preliminary interviews:	w/c 17th November 2025
Final Panel interviews:	w/c 8th December 2025